

# BMJ Open

BMJ Open is committed to open peer review. As part of this commitment we make the peer review history of every article we publish publicly available.

When an article is published we post the peer reviewers' comments and the authors' responses online. We also post the versions of the paper that were used during peer review. These are the versions that the peer review comments apply to.

The versions of the paper that follow are the versions that were submitted during the peer review process. They are not the versions of record or the final published versions. They should not be cited or distributed as the published version of this manuscript.

BMJ Open is an open access journal and the full, final, typeset and author-corrected version of record of the manuscript is available on our site with no access controls, subscription charges or pay-per-view fees (<http://bmjopen.bmj.com>).

If you have any questions on BMJ Open's open peer review process please email [editorial.bmjopen@bmj.com](mailto:editorial.bmjopen@bmj.com)

# BMJ Open

## Emergency Hospital Care for Adults with Suspected Seizures in the NHS in England 2007-2013: A Cross-Sectional Study

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2018-023352
Article Type:	Research
Date Submitted by the Author:	05-Apr-2018
Complete List of Authors:	Dickson, Jon; The University of Sheffield , The Academic Unit of Primary Medical Care Jacques, Richard; University of Sheffield, SchARR Reuber, Markus; The University of Sheffield Hick, Julian; Baslow Health Centre Campbell, Michael; University of Sheffield, SchARR Morley, Rebeka; Health IQ Grünewald, Richard; Sheffield Teaching Hospitals NHS Foundation Trust, Department of Neurosciences
Keywords:	Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Neurology < INTERNAL MEDICINE, Epilepsy < NEUROLOGY

SCHOLARONE™  
Manuscripts

**Emergency Hospital Care for Adults with Suspected Seizures in the NHS in England 2007-2013: A Cross-Sectional Study**

Jon M Dickson\*, Richard Jacques, Markus Reuber, Julian Hick, Mike J Campbell, Rebeka Morley, Richard A Grünewald

\* Corresponding author: Jon M Dickson, The Academic Unit of Primary Medical Care, The Medical School, The University of Sheffield, Room 215, 2nd Floor, Samuel Fox House, Northern General Hospital, Herries Road, Sheffield, S5 7AU. j.m.dickson@sheffield.ac.uk, 0114 222 2081 (tel), 0114 222 2219 (fax).

Keywords: neurology, epilepsy, health services, quality improvement

Word count: 2,873

**Aims**

To quantify the frequency, characteristics, geographical variation and costs of emergency hospital care for suspected seizures.

**Design**

Cross-sectional study using routinely collected data (Hospital Episode Statistics, HES).

**Setting**

The National Health Service (NHS) in England 2007-2013.

**Participants**

Adults who attended an emergency department (ED) or were admitted to hospital.

**Results**

In England (population 2011: 53.11 million, 41.77 million adults), suspected seizures gave rise to 53,128 unscheduled admissions per year amongst adults ( $\geq 18$  years). This is 47.5% of unscheduled admissions for neurological conditions and 0.76% of all unscheduled admissions. Only a small proportion of admissions for suspected seizures were coded as status epilepticus (3.5%) and a very small proportion as dissociative seizures (0.34%). The median length of stay for each admission was 1 day, the median cost for each admission was £1,650 (\$2,235) and the total cost of all admissions for suspected seizures in England was £93.6 million (\$130.6 million) per year. 22.4% of patients had more than one admission per year. There was significant geographical variability in the rate of admissions corrected for population age and gender differences and some areas had rates of admission which were consistently higher than the average.

**Conclusions**

Our data show that suspected seizures are the most common neurological cause of admissions to hospital in England, that re-admissions are common and that there is significant geographical variability in admission rates. The cause of the geographical variation is unknown; important factors are likely to include prevalence, deprivation and clinical practice and these require further investigation. Dissociative (non-epileptic) seizures are not adequately diagnosed during ED attendances and hospital admissions.

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

**Strengths and limitations of this study**

This is the first published study of unscheduled admissions for suspected seizures using hospital episode statistics (HES).

This study is based on data on all attendances at emergency departments (over 93 million) and all in-patient admissions to hospital (over 42 million) in England during a six-year period (2007-2013).

HES data uses ICD-10 for diagnostic coding facilitating comparisons with other national and international studies where ICD-10 is used.

Although the data cover the period 2007-2013, we are not aware of any factors that would have resulted in changes to these data which would impact on our conclusions in the intervening period.

For peer review only

## Introduction

Epilepsy is the most common chronic disabling neurological disease worldwide [1], it is an ambulatory care sensitive condition (ACSC) [2] and sub-optimal ambulatory (routine or scheduled) care can lead to unnecessary emergency care, which is often associated with morbidity and impaired quality of life [3]. Estimates vary internationally [4] [5] [6] [7] [8] [9] but most studies suggest that about 70% of people with epilepsy will become free of seizures with optimal treatment. The overall seizure freedom rate achieved in the United Kingdom (UK) is around 50% [10] [11] [12, 13]. This implies that approximately one-in-five patients with epilepsy may be having seizures that could be prevented [5]. In the UK, some epilepsy services are world-leading but the quality of care is geographically variable, and patients in many areas do not have access to optimal monitoring and treatment [14]. Many patients who have active epilepsy are not under the care of an epilepsy specialist [4] [15]. Epileptic seizures may give rise to potentially avoidable unplanned attendances at hospital emergency departments (EDs) (formerly known as accident and emergency departments, A&E) or admission to hospital, and management decisions may be complex, require expertise, training and guidance. However, after a seizure, patients are often seen by paramedics, junior doctors and physicians without particular expertise in epilepsy.

Precise estimates vary, but in England (population in 2011: 52.96 million, 42.96 million adults [16]), seizures give rise to 60,000 seizure-related ED attendances (2-3% of all attendances) (113 per 100,000 of the general population per year) [17], and 40,000 hospital admissions (76-148 per 100,000/year) which is 9.5% of all admissions for ACSCs [17] [18]. There were over one million emergency admissions for chronic ACSCs in England in the financial year 2011/12 and over 600,000 for acute conditions that should not normally require hospital admission [19]. Admissions in both categories have been rising, and suspected seizures are one of the largest contributors to these admissions. We should point out that, although most suspected seizures are epileptic [15], this is a diagnostically heterogeneous group and other conditions can mimic epilepsy [20]. We use the term 'suspected seizure' to encompass how this group of patients usually present to medical practitioners i.e. transient loss of consciousness and convulsions leading observers (usually not medical professionals) to suspect an epileptic seizure and to report this to emergency services.

The National Health Service (NHS) in the UK is tax-funded and free at the point of delivery. It is the provider of almost all health care in the UK, especially emergency care. The emergency care structure in the UK, with universal access to healthcare, and non-overlapping emergency services offers opportunities to study emergency presentations with suspected seizures which do not exist in many other countries. Most NHS services are commissioned locally by geographically based clinical commissioning groups (CCGs) which came into being on 01/04/13 (they were preceded by primary care trusts (PCTs) which had almost identical geographical boundaries) [21]. HES (Hospital Episode Statistics) is a data warehouse containing routinely collected details of all admissions, outpatient appointments and ED attendances at NHS hospitals in England. The data are collected during a patients' hospital attendance for the purpose of allowing hospitals to be paid for the care that they deliver but it is also a powerful tool for research. Our aim was to quantify the frequency, the characteristics and the costs of emergency department attendances and unplanned hospital admissions care for suspected seizures, and also to identify any geographical variation that may reflect disparities in ambulatory care or ED admission policies.

## Methods

### *Data Source and Case Ascertainment*

HES data was accessed by a third-party organisation (Health IQ) that searched the HES A&E database for attendances and the HES in-patient database for unscheduled/emergency in-patient admissions

in adults ( $\geq 18$  years) in the NHS in England during the period 1 April 2007 and 31 March 2013 (six financial years).

*Emergency Department (ED) Data*

We used the HES A&E Data Dictionary [22] central nervous system (CNS) codes (two character and three character): CNS excluding stroke (24), CNS epilepsy (241) and CNS other non-epilepsy (242). We used code 241 as a proxy for our target population of patients with suspected seizures. Although Emergency Department (ED) is now the preferred term in most countries this section of the HES data retains its historic title of HES A&E (accident and emergency) data.

*In-Patient Data*

We searched the in-patient database using diagnosis codes for diseases of the nervous system (chapter six of ICD-10, plus two codes from other chapters). Three separate searches were undertaken: 1) admissions where the primary diagnosis was suspected seizure, 2) admissions where the primary diagnosis was a neurological condition other than a suspected seizure (the full list of ICD-10 codes used to generate diagnostic categories are listed in the appendices), 3) admissions for dissociative convulsions. The following codes were used in the search for suspected seizures: G40 (epilepsy), G41 (status epilepticus) and R56.8 (other and unspecified convulsions). The following codes which are closely related to suspected seizures were not included: R56.0 (Febrile convulsions), P90 (Convulsions of new born), O15 (eclampsia) and R56.1 (post traumatic seizures). Stroke/TIA (G45/G56) was excluded because these are classified in ICD-10 as cerebrovascular diseases. F44.5 was used for dissociative convulsions. We also calculated the number of times patients were readmitted with the same codes over the study period. We calculated the time from first admission to either first readmission or to the end of the study period and plotted this using a Kaplan-Meier curve. We included data on costs for ED attendances and in-patient admissions.

*Geographical Variation in Seizure/Convulsions Admissions*

We calculated an age and sex directly standardised rate for the number of emergency admissions for each PCT. The numerator of the rate is calculated from Hospital Episode Statistics (HES) inpatient data and the denominator is the 2011 PCT population estimate from the Office for National Statistics (ONS) [1]. Adjustments were made for changes to the PCTs in terms of their names and codes and the merger of several trusts. The direct standardisation adjusted for age and sex with age categorised into three groups: 18-34, 35-64 and 65 and over. The age-sex specific standard population used in the analysis was calculated by grouping the populations of all PCTs from the ONS dataset [23].

To look at the distribution of directly standardised rates and to identify possibly outlying PCTs (low or high admission rates), funnel plots were drawn for each year [24]. The plots show the observed age and sex directly standardised rate for each PCT against the primary care trust population. In order to identify outliers, an over-dispersion model was used to draw control limits around the target outcome – that is, the weighted mean of the directly standardised rates [25]. This method allows an over-dispersion factor to be calculated that inflates the null variance and allows for any unexplained variation between the PCTs. If all PCTs were included in the estimate of the over-dispersion factor, then PCT that are truly outlying would inflate the parameter unduly and may not appear as outliers. Therefore when estimating the over-dispersion parameter a trimming approach was adopted to exclude the top and bottom 10% of PCTs based on their z-score (a scaled difference between the observed rate and the target rate). If no true outliers existed then the estimate of the over-dispersion parameter would only be minimally affected by this procedure.

*Patient and Public Involvement*

Patients and the public were not involved in this research.

## Results

### *Emergency Department HES Data*

During the study period (2007-13), 93,806,757 attendances were recorded at ED departments in England, a mean of 15,634,460 attendances per year. There were 146,729 epilepsy (code 241) attendances at ED (mean: 24,455 per year), representing 0.16% of all ED attendances and 0.33% of ED attendances that were given an HES A&E diagnosis code. The average cost of an ED attendance for suspected seizures (code 241) during the study period was £123 (\$172). The total costs related to ED attendances for suspected seizures was £18,047,667 (\$25,174,595) (£123 x 146,729), an average of £3,007,945 (\$4,195,766) per year.

### *In-Patient HES Data*

There were a total of 42,201,775 emergency admissions in the NHS in England between 1 April 2007 and 31 March 2013 (six financial years) of which 670,909 (1.6%) were for neurological conditions (after exclusions). 318,768 (47.5%) neurological admissions were for suspected seizures making this by far the most common neurological cause for unscheduled admissions (0.76% of unscheduled admissions for all causes). Figure A shows the number of unscheduled neurological admissions by diagnosis. There were 1,074 emergency admissions coded as dissociative convulsions (F44.5) during the study period (mean 179/annum, 0.34% of admissions for suspected seizures).

Suspected seizures accounted for a mean of 53,128 admissions per year, representing 0.76% (range 0.74-0.77%) of unscheduled admissions for all causes during the study period. 54.3% of the admissions for epilepsy/seizure/convulsion were coded as G40 (epilepsy), 42.2% were coded R56.8 (other and unspecified convulsions) and 3.5% were coded G41 (status epilepticus). 93.5% of admissions were via A&E and 3.6% were via GPs. More men (54.8%) than women (45.2%) had unplanned hospital admissions with these diagnostic codes. The median length of stay was 1 day (IQR=0-3, range 0-988). The median cost per admission was £1,650 (\$2,302) (IQR £1090-1856, range £0-£217,998) and the mean total cost per year was £93,619,197 (\$130,588,920) (during the study period).

### *Re-admissions*

Over the six-year study period, 77.6% of patients had one admission per year and 22.4% had more than one admission per year (15.1% had two admissions per year, 4.2% had 3 admissions per year and 3.1% had more than 3 admissions per year). Figure B shows Kaplan-Meier survival curves for time to first readmission. The curve indicates that overall there was a probability of 0.20 of readmission during the first year of the study and a 0.34 probability of readmission during the 6-year study period. The probability of re-admission (first year, full 6-years) for each ICD10 code (coding of first admission) was G40 (0.22 / 0.38), G41 (0.13 / 0.25) and R56.8 (0.11 / 0.18).

### *Geographical Variability in Admissions*

The weighted mean number of admissions for suspected seizures per 100,000 over the study period was 128.3. Figure C shows funnel plots of standardised admission rates for PCTs. Five PCTs (3.3%) were identified as being outliers more than 3SDs above the mean, when less than one would have been expected if PCTs were all behaving the same, and one PCT was found to be more than 3SDs below the mean. Data on individual PCTs is available in the appendices (see supplementary file).

## Discussion

### *In-Patient Admissions for Suspected Seizures*

Our data show that suspected seizures are the most common neurological cause of admission to hospital in England. We have deliberately used the term suspected seizure rather than epilepsy



because of the uncertainty around the diagnosis of sei-zures and epilepsy [20]. The cause of many seizures and other paroxysmal events involving collapse, and loss of consciousness may remain uncertain even after hospital admission and review by a specialist. This is further complicated by the difficulty distinguishing epileptic from psychogenic non-epileptic seizures [26] [27], inconsistencies between ILAE classifications and ICD-10 categories, and the transposition of doctors notes by hospital coders into ICD-10 codes. We used ICD-10 codes, G40, G41 and R56.8 to identify patients with suspected sei-zures. The same (or almost the same) ICD-10 codes have been used in other large studies of variation in admissions and quality of care for suspected seizures [28] [17]. There is some evidence from Canada that the diagnosis of epilepsy (G40 and G41) by hospital coders is specific but that use of the R56.8 code is required to improve sensitivity – at the cost of reducing overall specificity [29]. However, there may be geographical variation in coding especially where performance targets influence coding priorities and there have been no studies looking at coding accuracy in the UK. We propose that G40, G41 and R56.8 is the best combination of codes to identify patients with suspected sei-zures nevertheless the likely limitations should be acknowledged.

*Re-Admissions*

After an admission to hospital for a suspected seizure (or an attendance at ED) the aim of management should be to make an accurate diagnosis, manage urgent/emergency problems, optimise ongoing medical treatment (including referral to specialist outpatient services) and provide advice on self-care to reduce the risk of re-admission after discharge. Active epilepsy should trigger review by an epilepsy specialist to prevent further seizures and/or to refine the patients emergency care plan but this opportunity is often missed [15] [17] [30] [31] [20] and patients therefore remain at risk of further seizures and the associated morbidity [32], mortality [33] and health services costs [34] [35] of poorly controlled epilepsy. Our data show that 22.4% of patients had more than one admission per year and that overall there was a 34% chance of readmission after a suspected seizure within 6 years which provides further evidence of potentially avoidable admissions and poor quality care. However, quantification of avoidable admissions using HES data is complicated by the diagnostic uncertainty and the difficulty distinguishing between those cases that are truly ambulatory care sensitive (e.g. sub-optimally treated patients with active epilepsy) and those which are not (e.g. intractable epilepsy, first epileptic seizures which don't meet the criteria for epilepsy [36], and many more). Some national performance indicators are predicated on the notion that good quality scheduled care can prevent all admissions for seizures [28] [37, 38] which makes their validity doubtful.

*Geographical Variability and Service Provision*

There is significant geographical variability in the directly standardised admission rates and there are some geographical areas are consistently greater than 3SDs from the mean. This variability has not previously been reported in the published literature. As admission is determined both by rates of attendance to A&E and by emergency management policy, an “outlying” status is not necessarily a marker of poor ambulatory care. The analysis carried out here is capable of identifying CCGs that should review their ambulatory care for epilepsy and emergency care procedures for suspected seizures because their local admission statistics differ very markedly from national figures. Our research was not designed to investigate potential causes of the variability and the expected rate of hospital admissions per 100,000 is unknown. Factors which are likely to influence admission rates are the prevalence of epilepsy, deprivation, the quality of ambulatory care and local practice in the emergency care system such as care pathways (including the accessibility of neurological advice) and ED discharge protocols. Further research is required to investigate the causes of the variability demonstrated in this study.

### *Under-diagnosis of Dissociative Seizures*

The EPIC 2 [15] study showed that 7.4% of all in-patient admissions in a UK centre which resulted from a 999 call for a suspected seizure were caused by dissociative seizures (DS, ICD-10 code F44.5, also known as psychogenic nonepileptic seizures, PNES, or manifestations of non-epileptic attack disorder, NEAD) [15]. Based on this data we would expect 23,589 (7.4% x 318,768) (3,931 per year) admissions during the study period for DS but in our study the ICD-10 code for DS identified only 1,074 admissions in total (179/annum). Despite the fact that the nosology of DS is controversial and a number of different terms are used in the medical literature there is only one ICD-10 code for DS/PNES/NEAD, so it seems that miscoding is unlikely to be the cause of this discrepancy. The unexpectedly low number of cases coded as being admitted with DS adds to the evidence of under-diagnosis of DS by doctors in acute medical settings and of the misdiagnosis of DS as epileptic seizures [39] [40] [41] [42] [43]. In addition to case reports and case series of patients with DS receiving inappropriate emergency treatment for status epilepticus other indirect evidence for this problem comes from primary care studies demonstrating that non-expert diagnoses of epilepsy are regularly inaccurate and studies based in secondary care demonstrating that the mean diagnostic delay of DS is several years, with most patients with DS initially receiving treatment for epilepsy [44] [45] [46]. It may be that many patients who were admitted during the study period with a DS were actually coded using G40, G41 or R56.8. More research is required to accurately quantify the number of unplanned hospital admissions with DS, but as the management of dissociative seizures is very different from that of epileptic seizures, this observation provokes concern that the ED management of psychogenic seizures may be suboptimal.

### *A&E Data*

The HES A&E data dictionary uses a crude system of 58 diagnosis codes (at three-character level). Coding is done by individual clinicians many of who are junior doctors who have not had any training for this role. Using the HES A&E diagnosis code 241 (CNS epilepsy) for case ascertainment shows an average of 24,455 attendances per year that is significantly less than the number of admissions for suspected seizures based on the in-patient data. Many A&E attendances were classified as “unknown” or “diagnosis not classifiable” and it is not clear how the other two HES A&E neurology codes relate to the diagnosis of epilepsy. We conclude that HES A&E data is not of sufficient quality to make robust estimates of the number of attendances related to suspected seizures. The Emergency Care Data Set (ECDS) will supersede the current ED data and diagnosis codes will be based on the SNOMED-CT diagnostic codes [47] which may improve the quality of the data [48].

### *Competing Interests, Ethics and Acknowledgements*

This work was supported by UCB Pharma Ltd. through an educational grant the University of Sheffield (JMD, RAG, MR, JH) and consultancy fees to Health IQ (RM). UCB had no editorial control on the contents. The work was approved by the University of Sheffield research ethics committee (project number 001932). The HES data was provided by Health IQ (a real world data company that has access to HES data), in an aggregated, non-identifiable and suppressed format in line with NHS Digital guidelines.

### *Data Sharing Statement*

No unpublished data from this study is available.

### *Contributorship Statement*

The idea for the study came from RAG. JMD was the Chief Investigator and he worked with all the authors to develop the protocol. JMD, JH and RJ took the lead with data analysis. JMD took the lead with writing the manuscript. All authors contributed to the manuscript and approved the final version.

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

Figure A: Neurological diagnoses ranked by number of emergency hospital admissions between 31/04/07 and 31/03/13. Suspected seizures = G40 + G41 + R56.8.

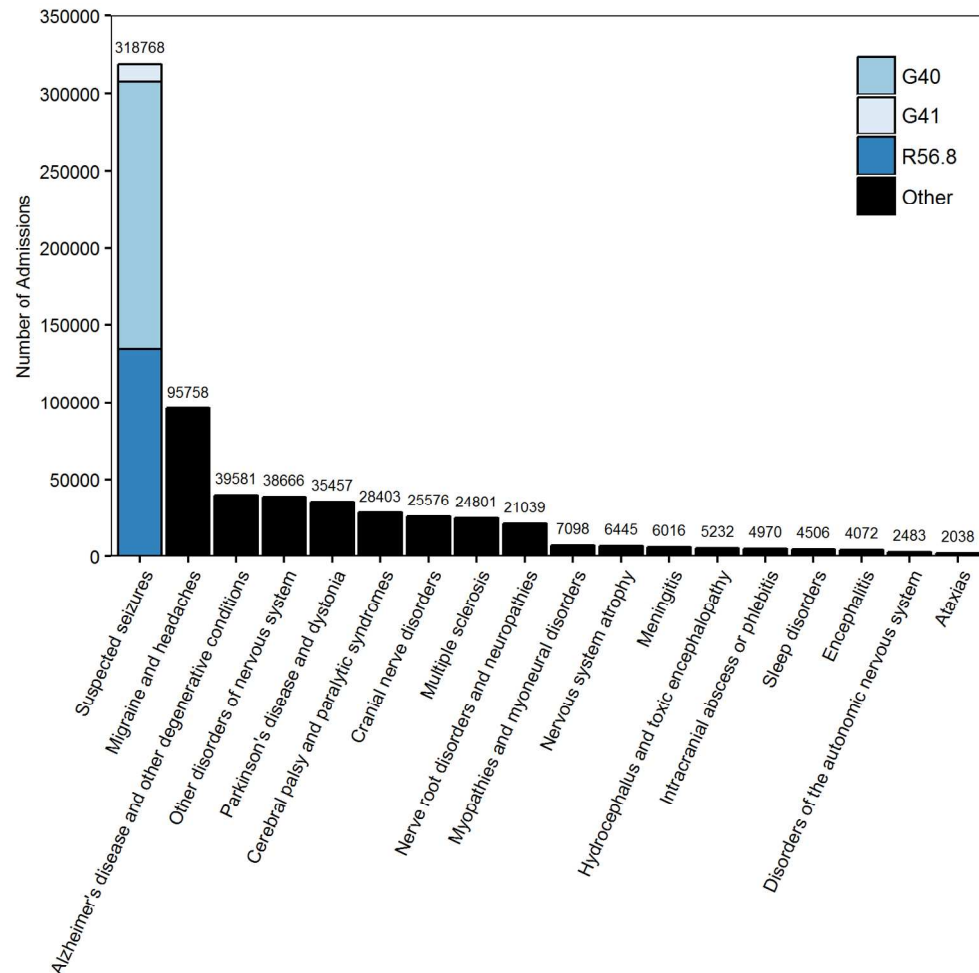
Figure B: Kaplan-Meier plots showing the time to first readmission after a suspected seizure when the first admission was for G40 + G41 + R56.8, G40, G41, R56.8. ICD-10 codes: G40 (epilepsy), G41 (status epilepticus) and R56.8 (other and unspecified convulsions).

Figure C: Funnel plots showing the directly standardised emergency admission rate per 100,000 of the adult population 2007-2013 in each PCT. (A) G40 + G41 + R56.8, (B) G40, (C) R56.8. There was not enough data to age-sex standardise the G41 diagnosis code. Each dot represents a PCT, the solid line shows the weighted mean for the standardised admission rate, and the dashed and dotted line shows 2 and 3 standard deviations from the mean respectively. ICD-10 codes: G40 (epilepsy), G41 (status epilepticus) and R56.8 (other and unspecified convulsions).

## References

1. Banerjee, P.N., D. Filippi, and W. Allen Hauser, *The descriptive epidemiology of epilepsy-a review*. *Epilepsy Res*, 2009. **85**(1): p. 31-45.
2. Bardsley, M., et al., *Is secondary preventive care improving? Observational study of 10-year trends in emergency admissions for conditions amenable to ambulatory care*. *BMJ Open*, 2013. **3**: p. e002007.
3. Gupta, S., et al., *Understanding the burden of idiopathic generalized epilepsy in the United States, Europe, and Brazil: An analysis from the National Health and Wellness Survey*. *Epilepsy Behav*, 2016. **55**: p. 146-56.
4. Thurman, D.J., et al., *Health-care access among adults with epilepsy: The U.S. National Health Interview Survey, 2010 and 2013*. *Epilepsy Behav*, 2015.
5. Moran, N.F., et al., *Epilepsy in the United Kingdom: seizure frequency and severity, anti-epileptic drug utilization and impact on life in 1652 people with epilepsy*. *Seizure*, 2004. **13**(6): p. 425-33.
6. *Relationship Between Seizure Frequency and Costs and Quality of Life of Outpatients with Partial Epilepsy in France, Germany and the United Kingdom*.
7. *ILAE Commission on the Burden of Epilepsy, Subcommittee on the Economic Burden of Epilepsy: Final report 1998-2001*.
8. Sander, J.W., *The Use of Antiepileptic Drugs - Principles and Practice*. *Epilepsia*, 2004. **45**(Suppl. 6): p. 28-34.
9. Kwan, P. and M.J. Brodie, *Early identification of refractory epilepsy*. *The New England Journal of Medicine*, 2000. **342**(5): p. 319.
10. Association of British Neurologists, *Acute Neurology services survey 2014*. 2014.
11. Jon M Dickson, Peter A Scott, and Markus Reuber, *Epilepsy Service Provision in the National Health Service in England in 2012*. *Seizure*, 2015. **30**: p. 26-31.
12. Pearson, M., et al., *National Audit of Seizure Management in Hospitals (Clinical Report)*. 2012.
13. Pearson, M., et al., *National Audit of Seizure Management in Hospitals (Clinical Report)*. 2014.
14. Dickson, J.M., P.A. Scott, and M. Reuber, *Epilepsy service provision in the National Health Service in England in 2012*. *Seizure*, 2015. **30**: p. 26-31.
15. Dickson, J., et al., *Cross-sectional study of the hospital management of adult patients with a suspected seizure (EPIC2)*. *BMJ Open*, 2017. **7**: p. e015696.
16. Office for National Statistics. *Time series: England population mid-year estimate*. 2018 [cited 2018 15/02/18]; Available from: [www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/timeseries/enpop/pop](http://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/timeseries/enpop/pop).
17. Dixon, P., et al., *National Audit of Seizure management in Hospitals (NASH): results of the national audit of epilepsy in the UK*. *BMJ Open*, 2015. **5**: p. e007325.
18. Tian, Y., A. Dixon, and H. Gao, *Emergency hospital admissions for ambulatory care-sensitive conditions: identifying the potential for reductions*, in *Data Briefing*. 2012, The King's Fund.
19. The NHS Information Centre, *CCG outcomes indicator set - emergency admissions*. 2013.
20. Malmgren, K., M. Reuber, and R. Appleton, *Differential diagnosis of epilepsy*, in *Oxford Textbook of Epilepsy and Epileptic Seizures 2013*, Oxford University Press.
21. Fund., T.K. *The new NHS: clinical commissioning groups*. 04/01/18]; Available from: <https://www.kingsfund.org.uk/projects/new-nhs/clinical-commissioning-groups>.
22. Health and Social Care Information Centre. *HES A&E Data Dictionary*. January 2016]; Available from: <http://www.hscic.gov.uk/article/3966/HES-AE-Data-Dictionary>.
23. Office for National Statistics. *Primary Care Organisations Mid-Year Population Estimates, Mid 2011 (Census Based)*. Available from: <http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-297507>.

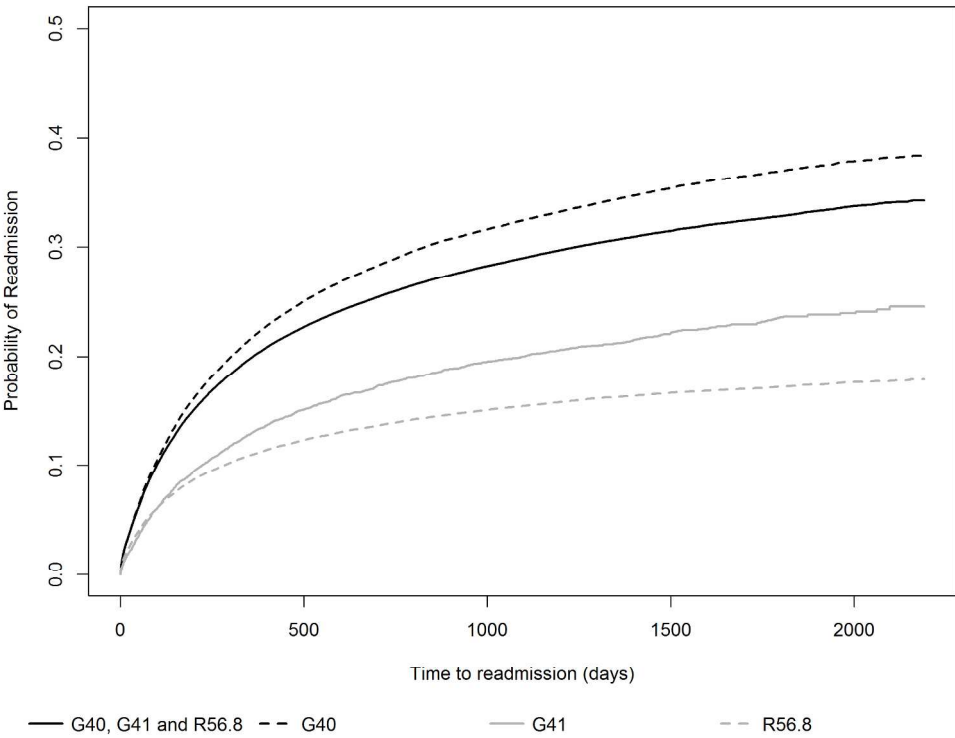
24. Spiegelhalter, D., *Funnel plots for comparing institutional performance*. . Stat Med, 2005. **24**: p. 1185-202.
25. Spiegelhalter, D.J., *Handling over-dispersion of performance indicators*. Qual Saf Health Care, 2005. **14**(5): p. 347-51.
26. Wasserman, D. and M. Herskovitz, *Epileptic vs psychogenic nonepileptic seizures: a video-based survey*. Epilepsy and Behaviour, 2017. **73**: p. 42-45.
27. Jackson, A., L. Teo, and U. Seneviratne, *Challenges in the first seizure clinic for adult patients with epilepsy*. Epileptic Disorders, 2016. **18**: p. 305-314.
28. NHS England, *The NHS Atlas of Variation in Healthcare*. 2015.
29. Jette, N., et al., *How accurate is ICD coding for epilepsy?* Epilepsia, 2010. **51**(1): p. 62-9.
30. National Institute of Clinical Excellence, *The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care*. 2012.
31. National Institute for Health and Care Excellence, *Transient loss of consciousness ('blackouts') management in adults and young people*. 2010.
32. Baker, G., A. Jacoby, and B. D., *Quality of life of people with epilepsy: a European study*. Epilepsia, 1997. **38**: p. 353-362.
33. Lhatoo, S., et al., *Mortality in Epilepsy in the First 11 to 14 Years after Diagnosis: Multivariate Analysis of a Long-Term, Prospective, Population-Based Cohort*. Annals of Neurology, 2001. **2001**: p. 336-344.
34. Manjunath, R., et al., *Burden of uncontrolled epilepsy in patients requiring an emergency room visit or hospitalization*. Neurology, 2012. **79**: p. 1908-1916.
35. Galarraga, J., R. Mutter, and J. Pines, *Costs associated with ambulatory care sensitive conditions across hospital-based settings*. Academic Emergency Medicine, 2015. **22**: p. 172-181.
36. Fisher, R.S., et al., *ILAE official report: a practical clinical definition of epilepsy*. Epilepsia, 2014. **55**(4): p. 475-82.
37. NHS England, *CCG Outcomes Indicator Set 2014/15: technical guidance*. December 2013.
38. Department of Health, *The NHS Outcomes Framework 2015/16*. 2014.
39. Reuber, M., et al., *Clinical significance of recurrent psychogenic nonepileptic seizure status*. Journal of Neurology, 2003. **250**(11): p. 1355-1362.
40. Reuber, M., et al., *Failure to recognize psychogenic nonepileptic seizures may cause death*. Neurology, 2004. **62**(5): p. 834-835.
41. Gunatilake, S., H. De Silva, and G. Ranasinghe, *Twenty-seven venous cutdowns to treat pseudostatus epilepticus*. 1997. **6**(1): p. 71-72.
42. Howell, S., L. Owen, and D. Chadwick, *Pseudostatus epilepticus*. Quarterly Journal of Medicine, 1989. **71**(266): p. 507-519.
43. Holtkamp, M., et al., *Diagnosis of psychogenic nonepileptic status epilepticus in the emergency setting*. Neurology, 2006. **66**(11): p. 1727-1729.
44. Leach, J.P., et al., *Epilepsy in the UK: misdiagnosis, mistreatment, and undertreatment? The Wrexham area epilepsy project*. Seizure, 2005. **14**(7): p. 514-20.
45. Reuber, M., et al., *Diagnostic delay in psychogenic nonepileptic seizures*. Neurology, 2002. **2002**(58): p. 493-495.
46. Kerr, W., et al., *Diagnostic delay in psychogenic seizures and the association with anti-seizure medication trials*. . Seizure, 2016. **40**: p. 123-126.
47. SNOMED International. *SNOMED CT*. [Accessed 04/01/18]; Available from: <https://www.snomed.org/snomed-ct>.
48. Dickson, J., S. Mason, and A. Bailey, *Emergency department diagnostic codes: useful data?* Emergency Medicine Journal, 2017. **34**: p. 627.



Neurological diagnoses ranked by number of emergency hospital admissions between 31/04/07 and 31/03/13. Suspected seizures = G40 + G41 + R56.8.

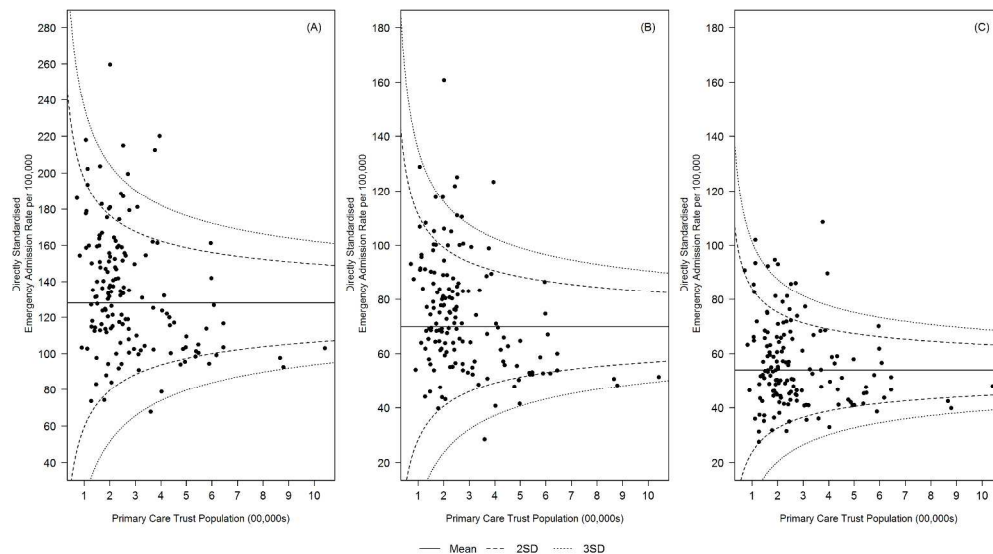
152x152mm (300 x 300 DPI)





Kaplan-Meier plots showing the time to first readmission after a suspected seizure when the first admission was for G40 + G41 + R56.8, G40, G41, R56.8. ICD-10 codes: G40 (epilepsy), G41 (status epilepticus) and R56.8 (other and unspecified convulsions).

228x177mm (300 x 300 DPI)



Funnel plots showing the directly standardised emergency admission rate per 100,000 of the adult population 2007-2013 in each PCT. (A) G40 + G41 + R56.8, (B) G40, (C) R56.8. There was not enough data to age-sex standardise the G41 diagnosis code. Each dot represents a PCT, the solid line shows the weighted mean for the standardised admission rate, and the dashed and dotted line shows 2 and 3 standard deviations from the mean respectively. ICD-10 codes: G40 (epilepsy), G41 (status epilepticus) and R56.8 (other and unspecified convulsions).

304x177mm (300 x 300 DPI)



1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

PCT CODE	PCT NAME	Rate Y1	Rate Y2	Rate Y3	Rate Y4	Rate Y5	Rate Y6	Rate All
5 E1	STOCKTON-ON-TEES TEACHING PCT	129.7	137.9	149.0	143.1	145.2	134.6	139.9
5A3	SOUTH GLOUCESTERSHIRE PCT	73.2	90.7	85.2	88.1	88.1	78.6	84.0
5A4	HAVERING PCT	104.8	98.1	123.1	126.4	125.9	91.9	111.8
5A5	KINGSTON	67.9	49.6	69.6	84.6	93.9	76.4	73.6
5A7	BROMLEY PCT	83.8	129.1	112.2	105.1	96.4	109.1	105.9
5A8	NHS GREENWICH	81.5	89.0	91.6	99.1	97.4	107.4	94.3
5A9	BARNET PRIMARY CARE TRUST	74.1	119.7	125.7	124.0	118.4	119.9	113.6
5AT	HILLINGDON PCT	112.6	102.9	124.7	116.7	106.0	127.7	115.1
5C1	ENFIELD PCT	68.7	94.0	110.6	93.1	80.7	104.1	91.9
5C2	BARKING AND DAGENHAM PCT	124.9	120.2	130.2	166.9	129.3	139.5	135.2
5C3	CITY AND HACKNEY TEACHING PCT	147.0	138.1	129.3	135.3	129.2	141.0	136.7
5C4	TOWER HAMLETS PRIMARY CARE TEAM	165.6	176.2	153.0	156.6	152.2	119.1	153.8
5C5	NEWHAM PRIMARY CARE TEAM	124.5	147.0	134.0	157.3	137.7	150.7	141.9
5C9	HARINGEY PCT	147.2	113.6	128.5	130.6	142.0	128.0	131.7
5CN	NHS HEREFORDSHIRE	88.0	100.8	94.7	114.8	103.7	84.1	97.7
5CQ	MILTON KEYNES PCT	109.0	133.6	110.7	137.8	128.7	103.2	120.5
5D7	NEWCASTLE PCT	155.5	131.7	145.7	145.0	152.8	150.5	146.9
5D8	NORTH TYNESIDE PCT	179.1	155.8	132.2	155.8	149.6	132.2	150.8
5D9	HARTLEPOOL PCT	154.5	142.1	207.4	179.9	207.9	225.6	186.2
5EF	NORTH LINCOLNSHIRE PCT	128.9	114.1	164.1	150.0	170.6	172.1	150.0
5EM	NOTTINGHAM CITY PCT	137.3	138.1	132.8	141.2	129.1	128.7	134.5
5ET	BASSETLAW	101.7	99.1	111.0	93.7	115.3	99.3	103.4
5F1	PLYMOUTH PRIMARY CARE TRUST	120.8	123.6	147.0	120.5	146.0	147.4	134.2
5F5	SALFORD PCT	152.9	131.9	162.6	151.1	141.0	142.8	147.1
5F7	STOCKPORT PCT	125.0	150.0	147.2	153.3	129.2	144.4	141.5
5FE	PORTSMOUTH CITY TEACHING PCT	155.5	146.3	147.7	155.5	156.9	124.8	147.8
5FL	BATH AND NORTH EAST SOMERSET PCT	127.2	129.6	99.7	102.4	113.6	113.5	114.3
5GC	LUTON PCT	105.8	120.4	110.3	117.2	153.2	158.2	127.5
5H1	HAMMERSMITH & FULHAM PCT	171.4	146.8	171.8	163.2	154.4	148.5	159.3
5H8	ROTHERHAM PCT	125.4	133.6	126.6	137.1	167.0	137.1	137.8
5HG	ASHTON LEIGH AND WIGAN PCT	135.7	151.8	152.7	156.8	158.7	153.7	151.6
5HP	BLACKPOOL PCT	174.0	171.3	192.8	187.3	231.9	204.6	193.6
5HQ	BOLTON PCT	146.5	137.4	127.7	138.3	125.3	148.9	137.4
5HX	EALING PCT	139.6	137.6	149.4	147.5	177.0	174.6	154.3
5HY	HOUNSLOW PCT	138.7	159.6	149.1	164.9	156.5	138.1	151.1
5J2	WARRINGTON PCT	141.7	142.1	175.0	144.2	192.8	163.5	159.9
5J4	KNOWSLEY	242.3	211.7	200.3	193.1	177.5	189.2	202.3
5J5	OLDHAM PRIMARY CARE TRUST	176.3	184.3	171.2	192.7	223.9	148.7	182.8
5J6	CALDERDALE PCT	161.9	163.6	167.6	169.9	159.8	159.6	163.7
5J9	DARLINGTON PCT	150.7	165.9	142.3	189.0	156.4	122.1	154.4
5JE	BARNSELEY PCT	93.5	124.8	126.3	117.2	110.3	109.1	113.5
5JX	BURY PRIMARY CARE TRUST	129.2	138.0	107.5	158.4	135.8	118.3	131.2
5K3	SWINDON PCT	89.8	114.8	124.0	117.4	121.4	130.2	116.3
5K5	BRENT PCT	125.1	139.9	129.3	132.7	116.8	148.6	132.1
5K6	HARROW PCT	66.8	83.0	81.4	100.7	92.0	103.9	88.0
5K7	CAMDEN PRIMARY CARE TRUST	136.3	139.2	143.1	95.8	109.1	124.6	124.7
5K8	ISLINGTON PRIMARY CARE TRUST	147.3	174.4	206.5	159.0	162.4	151.9	166.9
5K9	CROYDON PRIMARY CARE TRUST	124.3	119.8	146.6	132.9	140.8	145.7	135.0
5KF	GATESHEAD PRIMARY CARE TRUST	154.0	180.2	175.7	152.5	173.9	157.3	165.6
5KG	SOUTH TYNESIDE PCT	139.6	154.8	152.9	194.9	164.4	152.8	159.9
5KL	SUNDERLAND TEACHING PRIMARY CARE TRUST	163.6	168.3	178.6	133.1	120.4	123.4	147.9
5LM	MIDDLESBROUGH PCT	199.0	225.1	218.1	208.1	233.1	225.3	218.1
5L1	SOUTHAMPTON CITY PCT	129.8	193.0	184.2	182.7	166.2	197.3	175.5
5L3	NHS MEDWAY	120.6	102.3	114.9	119.3	112.6	114.0	114.0
5LA	KENSINGTON AND CHELSEA PCT	101.3	118.8	118.8	118.5	138.4	112.6	118.1
5LC	WESTMINSTER PCT	127.7	124.7	121.5	123.5	135.7	111.2	124.1
5LD	LAMBETH PCT	196.3	142.6	179.7	203.3	186.1	224.3	188.7
5LE	SOUTHWARK PCT	149.3	145.0	139.1	189.5	164.4	166.2	158.9
5LF	LEWISHAM PCT	148.6	126.6	148.7	133.0	131.5	156.2	140.8
5LG	WANDSWORTH PCT	126.5	148.3	130.7	122.7	142.7	129.5	133.4
5LH	TAMESIDE AND GLOSSOP PRIMARY CARE TRUST	132.0	142.6	170.6	219.8	214.9	201.0	180.2
5LQ	BRIGHTON AND HOVE CITY TEACHING PCT	136.4	163.9	145.8	186.6	180.4	162.0	162.5
5M1	SOUTH BIRMINGHAM PCT	164.5	177.7	176.5	191.7	189.2	176.3	179.3
5M2	SHROPSHIRE COUNTY PRIMARY CARE TRUST	79.7	78.8	92.4	108.4	106.0	100.3	94.3
5M3	WALSALL TEACHING PCT	131.2	135.0	131.7	128.5	120.0	111.7	126.4
5M6	RICHMOND & TWICKENHAM	74.0	60.6	66.6	89.6	102.4	105.5	83.1
5M7	SUTTON & MERTON PCT	105.5	116.4	116.1	109.4	103.0	109.6	110.0
5M8	NORTH SOMERSET PCT	90.2	117.6	118.5	126.8	116.8	106.8	112.8
5MD	COVENTRY PRIMARY CARE TRUST	132.9	146.3	155.1	165.5	173.5	180.2	158.9
5MK	TELFORD & WREKIN PRIMARY CARE TRUST	90.0	94.6	130.2	106.2	134.8	132.8	114.8
5MV	WOLVERHAMPTON CITY PRIMARY CARE TRUST	124.1	109.5	149.0	127.0	153.4	137.1	133.4
5MX	HEART OF BIRMINGHAM TEACHING PCT	154.7	150.7	176.5	200.4	151.6	151.8	164.3
5N1	LEEDS PCT	141.2	171.2	162.7	162.8	174.3	155.6	161.3
5N2	KIRKLEES PCT	113.0	138.1	133.5	150.2	143.8	107.1	130.9
5N3	WAKEFIELD DISTRICT PCT	159.8	154.1	176.0	163.8	143.5	137.1	155.7
5N4	SHEFFIELD PCT	85.9	88.9	106.1	104.9	107.9	107.6	100.2
5N5	DONCASTER PCT	104.9	87.8	115.4	124.1	146.8	125.2	117.4
5N6	DERBYSHIRE COUNTY PCT	86.6	93.0	97.2	96.8	106.5	86.2	94.4
5N7	DERBY CITY PCT	110.6	132.7	128.8	133.8	145.3	129.5	130.1
5N8	NHS NOTTINGHAMSHIRE COUNTY	94.0	103.1	100.7	93.5	105.4	93.7	98.4
5N9	LINCOLNSHIRE PCT	96.5	105.7	108.6	116.2	129.2	126.1	113.7
5NA	REDBRIDGE PCT	115.8	124.3	135.7	128.8	109.0	114.8	121.4
5NC	WALTHAM FOREST PCT	127.4	135.4	163.8	172.8	166.8	168.3	155.8
5ND	COUNTY DURHAM PCT	111.8	123.0	130.0	143.8	141.9	142.5	132.2
5NE	CUMBRIA TEACHING PCT	132.6	127.3	126.0	121.3	121.2	113.5	123.7
5NF	NORTH LANCASHIRE TEACHING PCT	101.7	107.9	129.3	133.4	119.0	122.9	119.0
5NG	CENTRAL LANCs PCT	114.2	123.1	125.9	137.1	120.4	130.9	125.3
5NH	EAST LANCASHIRE TEACHING PCT	142.3	117.9	159.3	163.3	159.6	155.3	149.6
5NJ	SEFTON PCT	199.1	137.3	154.1	147.2	119.5	157.6	152.5
5NK	WIRRAL PCT	183.8	206.6	202.2	223.6	229.2	244.5	215.0
5NL	LIVERPOOL PCT	222.8	226.1	203.9	222.9	215.6	183.8	212.5
5NM	HALTON & ST HELENS PCT	144.1	180.0	162.6	178.2	185.1	196.1	174.4
5NN	WESTERN CHESHIRE PCT	129.7	156.9	174.8	155.2	132.8	122.8	145.3
5NP	CENTRAL AND EASTERN CHESHIRE PCT	131.2	172.5	195.1	188.4	150.4	134.1	162.0
5NQ	HEYWOOD MIDDLETON & ROCHDALE PCT	150.5	167.6	157.1	182.8	166.7	167.4	165.3
5NR	TRAFFORD PCT	112.4	129.3	154.5	136.9	161.8	146.2	140.2
5NT	MANCHESTER PCT	203.6	214.8	197.8	223.7	232.9	248.9	220.3
5NV	NORTH YORKSHIRE AND YORK PCT	93.3	95.7	104.9	108.9	113.6	104.4	103.5
5NW	EAST RIDING OF YORKSHIRE PCT	115.1	125.9	113.9	140.5	119.3	99.3	119.0
5NX	HULL TEACHING PCT	241.5	253.1	268.3	266.6	268.2	261.0	259.8
5NY	BRADFORD & AIREDALE PCT	150.8	167.4	159.1	171.9	172.9	146.0	161.4
5P1	SOUTH EAST ESSEX PCT	100.9	106.0	102.3	113.3	110.6	114.7	108.0
5P2	BEDFORDSHIRE PCT	89.6	100.2	101.9	107.1	105.8	106.0	101.8
5P5	SURREY PCT	81.9	93.5	96.3	94.6	94.3	95.3	92.6
5P6	WEST SUSSEX PCT	99.1	112.9	120.7	122.0	127.5	117.3	116.6
5P7	EAST SUSSEX DOWNS & WEALD PCT	99.0	103.7	93.6	98.1	90.7	117.8	100.5
5P8	HASTINGS & ROTHER PCT	148.5	139.1	149.2	143.1	109.6	99.7	131.5
5P9	NHS WEST KENT	99.2	102.9	104.1	103.1	109.6	111.1	105.0
5PA	LEICESTERSHIRE COUNTY & RUTLAND PCT	96.5	89.6	93.4	106.5	106.7	110.1	100.5
5PC	LEICESTER CITY PCT	179.4	169.4	198.9	193.8	201.6		

Diagnosis Group Label	ICD-10	ICD10 Description
Migraine and headaches	G43	Migraine
	G44	Other headache syndromes
Alzheimer's disease and....	G30	Alzheimer's disease
	G31	Other degenerative diseases of nervous system, not elsewhere classified
	G32	Other degenerative disorders of nervous system in diseases classified elsewhere
Other disorders of nervous system	G93	Other disorders of brain
	G94	Other disorders of brain in diseases classified elsewhere
	G95	Other diseases of spinal cord
	G96	Other disorders of central nervous system
	G97	Post-procedural disorders of nervous system, not elsewhere classified
	G98	Other disorders of nervous system, not elsewhere classified
	G99	Other disorders of nervous system in diseases classified elsewhere
Parkinson's disease and dystonia	G20	Parkinson's disease
	G21	Secondary parkinsonism
	G23	Other degenerative diseases of basal ganglia
	G24	Dystonia
	G25	Other extrapyramidal and movement disorders
Cerebral palsy and paralytic syndromes	G80	Cerebral palsy
	G81	Hemiplegia
	G82	Paraplegia and tetraplegia
	G83	Other paralytic syndromes
Cranial Nerve Disorders	G50	Disorders of trigeminal nerve
	G51	Facial nerve disorders
	G52	Disorders of other cranial nerves
	G53	Cranial nerve disorders in diseases classified elsewhere
Multiple sclerosis	G35	Multiple sclerosis
	G36	Other acute disseminated demyelination
	G37	Other demyelinating diseases of central nervous system
Nerve Root Disorders and neuropathies	G54	Nerve root and plexus disorders
	G55	Nerve root and plexus compressions in diseases classified elsewhere
	G56	Mono-neuropathies of upper limb

	G57	Mono-neuropathies of lower limb
	G58	Other mono-neuropathies
	G59	Mono-neuropathy in diseases classified elsewhere
	G60	Hereditary and idiopathic neuropathy
	G61	Inflammatory polyneuropathy
	G62	Other polyneuropathies
	G63	Polyneuropathy in diseases classified elsewhere
	G64	Other disorders of peripheral nervous system
Myopathies and myoneural disorders	G70	Myasthenia gravis and other myo-neural disorders
	G71	Primary disorders of muscles
	G72	Other myopathies
	G73	Disorders of myo-neural junction and muscle in diseases classified elsewhere
Nervous system atrophy	G12	Spinal muscular atrophy and related syndromes
	G13	Systemic atrophies primarily affecting central nervous system in diseases classified elsewhere
	G14	Post-polio syndrome
Huntington's disease	G10	Huntington's disease
Meningitis	G00	Bacterial meningitis, not elsewhere classified
	G01	Meningitis in bacterial diseases classified elsewhere
	G02	Meningitis in other infectious and parasitic diseases classified elsewhere
	G03	Meningitis due to other and unspecified causes
Hydrocephalus and toxic encephalopathy	G91	Hydrocephalus
	G92	Toxic encephalopathy
Intra-cranial abscess or phlebitis	G06	Intracranial and intra-spinal abscess and granuloma
	G07	Intracranial and intra-spinal abscess and granuloma in diseases classified elsewhere
	G08	Intracranial and intra-spinal phlebitis and thrombophlebitis
Sleep disorders	G47	Sleep disorders
Encephalitis	G04	Encephalitis, myelitis and encephalomyelitis
	G05	Encephalitis, myelitis and encephalomyelitis in diseases classified elsewhere
Disorders of the autonomic nervous system	G90	Disorders of autonomic nervous system
Ataxias	G11	Hereditary ataxia

The RECORD statement – checklist of items, extended from the STROBE statement, that should be reported in observational studies using routinely collected health data.

Item No.	STROBE items	Location in manuscript where items are reported	RECORD items	Location in manuscript where items are reported
<b>Title and abstract</b>				
1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found		RECORD 1.1: The type of data used should be specified in the title or abstract. When possible, the name of the databases used should be included.  RECORD 1.2: If applicable, the geographic region and timeframe within which the study took place should be reported in the title or abstract.  RECORD 1.3: If linkage between databases was conducted for the study, this should be clearly stated in the title or abstract.	pg 1  pg 1  114.
<b>Introduction</b>				
2	Explain the scientific background and rationale for the investigation being reported			pg 3
3	State specific objectives, including any prespecified hypotheses			pg 3
<b>Methods</b>				
4	Present key elements of study design early in the paper			pgs 3-4
5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection			3-4

Participants	6	<p>(a) <i>Cohort study</i> - Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up</p> <p><i>Case-control study</i> - Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls</p> <p><i>Cross-sectional study</i> - Give the eligibility criteria, and the sources and methods of selection of participants</p> <p>(b) <i>Cohort study</i> - For matched studies, give matching criteria and number of exposed and unexposed</p> <p><i>Case-control study</i> - For matched studies, give matching criteria and the number of controls per case</p>		<p>RECORD 6.1: The methods of study population selection (such as codes or algorithms used to identify subjects) should be listed in detail. If this is not possible, an explanation should be provided.</p> <p>RECORD 6.2: Any validation studies of the codes or algorithms used to select the population should be referenced. If validation was conducted for this study and not published elsewhere, detailed methods and results should be provided.</p> <p>RECORD 6.3: If the study involved linkage of databases, consider use of a flow diagram or other graphical display to demonstrate the data linkage process, including the number of individuals with linked data at each stage.</p>	3-4
Variables	7	<p>Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable.</p>		<p>RECORD 7.1: A complete list of codes and algorithms used to classify exposures, outcomes, confounders, and effect modifiers should be provided. If these cannot be reported, an explanation should be provided.</p>	3-4
Data sources/ measurement	8	<p>For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group</p>			3-4

Bias	9	Describe any efforts to address potential sources of bias			3-4
Study size	10	Explain how the study size was arrived at			3-4
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why			3-4
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) <i>Cohort study</i> - If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> - If applicable, explain how matching of cases and controls was addressed <i>Cross-sectional study</i> - If applicable, describe analytical methods taking account of sampling strategy (e) Describe any sensitivity analyses			3-4
Data access and cleaning methods		..		RECORD 12.1: Authors should describe the extent to which the investigators had access to the database population used to create the study population.	3-4

					RECORD 12.2: Authors should provide information on the data cleaning methods used in the study.	3-4
Linkage		..			RECORD 12.3: State whether the study included person-level, institutional-level, or other data linkage across two or more databases. The methods of linkage and methods of linkage quality evaluation should be provided.	N/A
<b>Results</b>						
Participants	13		(a) Report the numbers of individuals at each stage of the study ( <i>e.g.</i> , numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed) (b) Give reasons for non-participation at each stage. (c) Consider use of a flow diagram		RECORD 13.1: Describe in detail the selection of the persons included in the study ( <i>i.e.</i> , study population selection) including filtering based on data quality, data availability and linkage. The selection of included persons can be described in the text and/or by means of the study flow diagram.	3-4
Descriptive data	14		(a) Give characteristics of study participants ( <i>e.g.</i> , demographic, clinical, social) and information on exposures and potential confounders (b) Indicate the number of participants with missing data for each variable of interest (c) <i>Cohort study</i> - summarise follow-up time ( <i>e.g.</i> , average and total amount) <i>Cohort study</i> - Report numbers of outcome events or summary measures over time <i>Case-control study</i> - Report numbers in each exposure			N/A
Outcome data	15					

		category, or summary measures of exposure <i>Cross-sectional study</i> - Report numbers of outcome events or summary measures				5
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period				N/A
Other analyses	17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses				5
<b>Discussion</b>						
Key results	18	Summarise key results with reference to study objectives				5-7
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias			RECORD 19.1: Discuss the implications of using data that were not created or collected to answer the specific research question(s). Include discussion of misclassification bias, unmeasured confounding, missing data, and changing eligibility over time, as they pertain to the study being reported.	
Interpretation	20	Give a cautious overall interpretation of results considering objectives,				15-7



		limitations, multiplicity of analyses, results from similar studies, and other relevant evidence			
Generalisability	21	Discuss the generalisability (external validity) of the study results			
Other Information					
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based			7
Accessibility of protocol, raw data, and programming code		..		RECORD 22.1: Authors should provide information on how to access any supplemental information such as the study protocol, raw data, or programming code.	7

\*Reference: Benchimol EI, Smeeth L, Guttman A, Harron K, Moher D, Petersen I, Sørensen HT, von Elm E, Langan SM, the RECORD Working Committee. The REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) Statement. *PLoS Medicine* 2015; in press.

\*Checklist is protected under Creative Commons Attribution (CC BY) license.

# BMJ Open

## Emergency Hospital Care for Adults with Suspected Seizures in the NHS in England 2007-2013: A Cross-Sectional Study

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2018-023352.R1
Article Type:	Research
Date Submitted by the Author:	21-Jun-2018
Complete List of Authors:	Dickson, Jon; The University of Sheffield , The Academic Unit of Primary Medical Care Jacques, Richard; University of Sheffield, SchARR Reuber, Markus; The University of Sheffield Hick, Julian; Baslow Health Centre Campbell, Michael; University of Sheffield, SchARR Morley, Rebeka; Health IQ Grünewald, Richard; Sheffield Teaching Hospitals NHS Foundation Trust, Department of Neurosciences
<b>Primary Subject Heading</b>:	Neurology
Secondary Subject Heading:	Emergency medicine, Epidemiology, Health services research
Keywords:	Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Neurology < INTERNAL MEDICINE, Epilepsy < NEUROLOGY

SCHOLARONE™  
Manuscripts

**Emergency Hospital Care for Adults with Suspected Seizures in the NHS in England 2007-2013: A Cross-Sectional Study**

Jon M Dickson\*, Richard Jacques, Markus Reuber, Julian Hick, Mike J Campbell, Rebeka Morley, Richard A Grünewald

\* Corresponding author: Jon M Dickson, The Academic Unit of Primary Medical Care, The Medical School, The University of Sheffield, Room 215, 2nd Floor, Samuel Fox House, Northern General Hospital, Herries Road, Sheffield, S5 7AU. j.m.dickson@sheffield.ac.uk, 0114 222 2081 (tel), 0114 222 2219 (fax).

Keywords: neurology, epilepsy, health services, quality improvement

Word count: 3,549

**Aims**

To quantify the frequency, characteristics, geographical variation and costs of emergency hospital care for suspected seizures.

**Design**

Cross-sectional study using routinely collected data (Hospital Episode Statistics).

**Setting**

The National Health Service (NHS) in England 2007-2013.

**Participants**

Adults who attended an emergency department (ED) or were admitted to hospital.

**Results**

In England (population 2011: 53.11 million, 41.77 million adults), suspected seizures gave rise to 50,111 unscheduled admissions per year amongst adults ( $\geq 18$  years). This is 47.1% of unscheduled admissions for neurological conditions and 0.71% of all unscheduled admissions. Only a small proportion of admissions for suspected seizures were coded as status epilepticus (3.5%) and a very small number of dissociative (non-epileptic) seizures. The median length of stay for each admission was 1 day, the median cost for each admission was £1,651 (\$2,175) and the total cost of all admissions for suspected seizures in England was £88.2 million (\$116.2 million) per year. 16.8% of patients had more than one admission per year. There was significant geographical variability in the rate of admissions corrected for population age and gender differences and some areas had rates of admission which were consistently higher than the average.

**Conclusions**

Our data show that suspected seizures are the most common neurological cause of admissions to hospital in England, that re-admissions are common and that there is significant geographical variability in admission rates. This variability has not previously been reported in the published literature. The cause of the geographical variation is unknown; important factors are likely to include prevalence, deprivation and clinical practice and these require further investigation. Dissociative seizures are not adequately diagnosed during ED attendances and hospital admissions.

**Strengths and limitations of this study**

This study is based on hospital episode statistics (HES) data which includes all attendances at emergency departments (over 93 million) and all in-patient admissions to hospital (over 42 million) in England during a six-year period (2007-2013).

This is the first published study of unscheduled admissions for suspected seizures using HES data.

HES data uses ICD-10 for diagnostic coding facilitating comparisons with other national and international studies where ICD-10 is used.

We have assumed that HES diagnosis codes are accurate compared to gold standard clinical diagnoses for epilepsy and seizures but further research is required to confirm this.

## Introduction

Epilepsy is the most common chronic disabling neurological disease worldwide [1], it is an ambulatory care sensitive condition (ACSC) [2] and sub-optimal ambulatory (routine or scheduled) care can lead to unnecessary emergency care, which is often associated with morbidity and impaired quality of life [3]. Estimates vary internationally [4] [5] [6] [7] [8] [9] but most studies suggest that approximately 70% of people with epilepsy will become free of seizures with optimal treatment. The overall seizure freedom rate achieved in the United Kingdom (UK) is around 50% [10] [11] [12, 13]. This implies that approximately one-in-five patients with epilepsy may be having seizures that could be prevented [5]. In the UK, some epilepsy services are world-leading but the quality of care is geographically variable, and patients in many areas do not have access to optimal monitoring and treatment [14]. Many patients who have active epilepsy are not under the care of an epilepsy specialist [4] [15]. Epileptic seizures may give rise to potentially avoidable unplanned attendances at hospital emergency departments (EDs) (formerly known as accident and emergency departments, A&E) or admission to hospital, and management decisions may be complex, require expertise, training and guidance. However, after a seizure, patients are often seen by paramedics, junior doctors and physicians without particular expertise in epilepsy.

Precise estimates vary, but in England (population in 2011: 52.96 million, 42.96 million adults [16]), seizures give rise to 60,000 seizure-related ED attendances (2-3% of all attendances) (113 per 100,000 of the general population per year) [17], and 40,000 hospital admissions (76-148 per 100,000/year) which is 9.5% of all admissions for ACSCs [17] [18]. There were over one million emergency admissions for chronic ACSCs in England in the financial year 2011/12 and over 600,000 for acute conditions that should not normally require hospital admission [19]. Admissions in both categories have been rising, and suspected seizures are one of the largest contributors to these admissions. We should point out that, although most suspected seizures are epileptic [15], this is a diagnostically heterogeneous group and other conditions can mimic epilepsy [20]. We use the term 'suspected seizure' to encompass how this group of patients usually present to medical practitioners i.e. transient loss of consciousness and convulsions leading observers (usually not medical professionals) to suspect an epileptic seizure and to report this to emergency services.

The National Health Service (NHS) in the UK is tax-funded and free at the point of delivery. It is the provider of almost all health care in the UK, especially emergency care. The emergency care structure in the UK, with universal access to healthcare, and non-overlapping emergency services offers opportunities to study emergency presentations with suspected seizures which do not exist in many other countries. Most NHS services are commissioned locally by geographically based clinical commissioning groups (CCGs) which came into being on 01/04/13 (they were preceded by primary care trusts (PCTs) which had similar geographical boundaries) [21]. HES (Hospital Episode Statistics) is a data warehouse containing routinely collected data from all admissions, outpatient appointments and ED attendances at NHS hospitals in England. The data are collected during a patients' hospital attendance for the purpose of allowing hospitals to be paid for the care that they deliver but it is also a powerful tool for research. Our aims were to quantify the frequency, the characteristics and the costs of emergency department attendances and unplanned hospital admissions care for suspected seizures, and to identify geographical variation that may reflect disparities in ambulatory care or emergency care pathways such as ED admission guidelines.

## Methods

### *Data Source and Case Ascertainment*

HES data was accessed by a third-party organisation (Health IQ) that searched the HES A&E database for attendances and the HES in-patient database for unscheduled/emergency in-patient admissions in adults ( $\geq 18$  years) in the NHS in England during the period 1 April 2007 and 31 March 2013 (six

financial years). Six years of data was judged sufficient to explore re-admission rates after the index admission and the cut-off of 31/03/13 was chosen to avoid any potential disruption from 01/04/13 as CCGs came into being.

*Emergency Department (ED) Data*

We used the HES A&E Data Dictionary [22] central nervous system (CNS) codes (two character and three character): CNS excluding stroke (24), CNS epilepsy (241) and CNS other non-epilepsy (242). We used code 241 as a proxy for our target population of patients with suspected seizures. Although Emergency Department (ED) is now the preferred term in most countries this section of the HES data retains its historic title of HES A&E (accident and emergency) data.

*In-Patient Data*

We searched the in-patient database for admissions (spells) where  $\geq 1$  episode (a period under the care of an individual consultant) during the admission/spell had a primary diagnosis code for a disease of the nervous system. Three separate searches were undertaken: 1) admissions where the primary diagnosis was suspected seizure, 2) admissions where the primary diagnosis was a neurological condition other than a suspected seizure (the full list of ICD-10 codes used to generate diagnostic categories are listed in the appendices, we used ICD-10 chapter six plus two codes from other chapters), 3) admissions where the primary diagnosis was dissociative seizures. The following codes were used in the search for suspected seizures: G40 (epilepsy), G41 (status epilepticus) and R56.8 (other and unspecified convulsions). The following codes which are closely related to suspected seizures were not included: R56.0 (Febrile convulsions), P90 (Convulsions of new born), O15 (eclampsia) and R56.1 (post traumatic seizures). Stroke/TIA (G45/G56) was not included in any of the searches because these conditions are classified in ICD-10 as cerebrovascular diseases. F44.5 was used for dissociative convulsions/seizures. We also calculated the number of times patients were readmitted with the same codes over the study period. We calculated the time from first admission to either first readmission or to the end of the study period and plotted this using a Kaplan-Meier curve. We included data on costs for ED attendances and in-patient admissions. The cost of each A&E attendance was based on: (Health Resources Group (HRG) attributed to each attendance) + (Investigation and Treatment cost) x Market Forces Factor (MFF). The cost of each admission was based on: (HRG attributed to each admission + trim-point (base) cost + Added Bed days cost) x Market Forces Factor (MFF).

*Geographical Variation in Seizure/Convulsions Admissions*

We calculated an age and sex directly standardised rate for the number of emergency admissions for each PCT (151 PCTs in total). The numerator of the rate is calculated from Hospital Episode Statistics (HES) inpatient data and the denominator is the 2011 PCT population estimate from the Office for National Statistics (ONS) [1]. Adjustments were made for changes to the PCTs in terms of their names and codes and the merger of several trusts. The direct standardisation adjusted for age and sex with age categorised into three groups: 18-34, 35-64 and 65 and over. The age-sex specific standard population used in the analysis was calculated by grouping the populations of all PCTs from the ONS dataset [23].

To look at the distribution of directly standardised rates and to identify possibly outlying PCTs (low or high admission rates), funnel plots were drawn for each year [24]. The plots show the observed age and sex directly standardised rate for each PCT against the primary care trust population. In order to identify outliers, an over-dispersion model was used to draw control limits around the target outcome – that is, the weighted mean of the directly standardised rates [25]. This method allows an over-dispersion factor to be calculated that inflates the null variance and allows for any unexplained variation between the PCTs. If all PCTs were included in the estimate of the over-dispersion factor, then PCTs that are truly outlying would inflate the parameter unduly and may not

appear as outliers. Therefore when estimating the over-dispersion parameter a trimming approach was adopted to exclude the top and bottom 10% of PCTs ( $20\% \times 151 = 31$ ) based on their z-score (a scaled difference between the observed rate and the target rate). If no true outliers existed then the estimate of the over-dispersion parameter would only be minimally affected by this procedure.

#### *Patient and Public Involvement*

Patients and the public were not involved in this research.

## **Results**

### *Emergency Department HES Data*

During the study period (2007-13), 93,806,757 attendances were recorded at ED departments in England, a mean of 15,634,460 attendances per year. There were 146,729 epilepsy (code 241) attendances at ED (mean: 24,455 per year), representing 0.16% of all ED attendances and 0.33% of ED attendances that were given an HES A&E diagnosis code. The average cost of an ED attendance for suspected seizures (code 241) during the study period was £123 (\$172). The total costs related to ED attendances for suspected seizures was £18,047,667 (\$25,174,595) (£123 x 146,729), an average of £3,007,945 (\$4,195,766) per year.

### *In-Patient HES Data*

There were a total of 42,201,775 emergency admissions in the NHS in England between 1 April 2007 and 31 March 2013 (six financial years) of which 638,150 (1.5%) were for neurological conditions (after exclusions). 300,668 (47.1%) neurological admissions were for suspected seizures making this by far the most common neurological cause for unscheduled admissions (0.71% of unscheduled admissions for all causes). Figure 1 shows the number of unscheduled neurological admissions by diagnosis. There were 1,074 emergency admissions coded as dissociative convulsions (F44.5) during the study period (mean 179/annum).

Suspected seizures accounted for a mean of 50,111 admissions per year, representing 0.71% (range 0.67-0.74%) of unscheduled admissions for all causes during the study period. 54.3% of the admissions for epilepsy/seizure/convulsion were coded as G40 (epilepsy), 42.2% were coded R56.8 (other and unspecified convulsions) and 3.5% were coded G41 (status epilepticus). 93.4% of admissions were via A&E and 3.6% were via GPs. More men (54.6%) than women (45.4%) had unplanned hospital admissions with these diagnostic codes. The median length of stay was 1 day (IQR=0-3, range 0-988). The median cost per admission was £1,651 (\$2,1750) (IQR £1091-1858, range £0-£217,998) and the mean total cost per year was £88,217,138 (\$116,224,315) (during the study period).

### *Re-admissions*

Over the six-year study period, 83.2% of patients had one admission per year and 16.8% had more than one admission per year (12.1% had two admissions per year, 3.4% had 3 admissions per year and 1.3% had more than 3 admissions per year). Figure 2 shows Kaplan-Meier survival curves for time to first readmission. The curve indicates that overall there was a probability of 0.20 of readmission during the first year of the study and a 0.34 probability of readmission during the 6-year study period. The probability of re-admission (first year, full 6-years) for each ICD10 code (coding of first admission) was G40 (0.22 / 0.38), G41 (0.13 / 0.23) and R56.8 (0.11 / 0.18).

### *Geographical Variability in Admissions*

The weighted mean number of admissions for suspected seizures per 100,000 over the study period was 121.0. Figure 3a shows funnel plots of standardised admission rates for suspected seizures (G40 + G41 + R56.8) for each PCT (Figure 3b and 3c show rates for individual ICD-10 codes). Figure 3a



demonstrates that four PCTs (2.6%) were identified as being outliers more than 3SDs above the mean, when less than one would have been expected if PCTs were all behaving the same, and no PCT was found to be more than 3SDs below the mean. Data on individual PCTs is available in the appendices (see supplementary file).

Ethics

HES data was provided by Health IQ (a real world data company that has access to HES data), in an aggregated, non-identifiable and suppressed format in line with NHS Digital guidelines. The work was approved by the University of Sheffield research ethics committee (project number 001932).

**Discussion**

**In-Patient Admissions for Suspected Seizures**

Our data show that suspected seizures are the most common neurological cause of admission to hospital in England. We have deliberately used the term suspected seizure rather than epilepsy because of the uncertainty around the diagnosis of seizures and epilepsy [20]. The cause of many seizures and other paroxysmal events involving collapse, and loss of consciousness may remain uncertain even after hospital admission and review by a specialist. This is further complicated by the difficulty distinguishing epileptic from psychogenic non-epileptic seizures [26] [27], inconsistencies between ILAE classifications and ICD-10 categories, and the transposition of doctors notes by hospital coders into ICD-10 codes. We used ICD-10 codes, G40, G41 and R56.8 to identify patients with suspected seizures. The same (or almost the same) ICD-10 codes have been used in other large studies of variation in admissions and quality of care for suspected seizures [28] [29] [17]. There is evidence that HES diagnostic coding is accurate overall, but there is significant variability amongst the published studies [30]. Research from Canada shows that the diagnosis of epilepsy (G40 and G41) by hospital coders is specific but that the use of R56.8 is required to improve sensitivity – at the cost of reducing overall specificity [31]. There have been no similar studies in the UK looking specifically at seizures/epilepsy i.e. comparing HES ICD-10 diagnosis codes with a gold standard diagnosis.

The only previously published study using HES data [28] which is directly comparable to this study showed that seizures gave rise to 1.36% (interhospital range 1.2-1.6%) of all emergency admissions [28] which is approximately twice the rate that we found (0.71%; range 0.67-0.74%). Grainger et al included patients using primary and secondary diagnoses whereas our study exclusively used the primary diagnosis which probably accounts for the difference. There have been no published studies modelling the effects of different methods of case ascertainment on admissions rates in terms of primary and secondary diagnoses but there is likely to be a trade off between sensitivity and specificity using the different methods. We propose that, based on the current evidence, G40+G41+R56.8 is the best combination of codes to identify patients with suspected seizures. But we conclude that further research is required on the optimal method of identifying admissions for suspected seizures both in terms of ICD-10 codes and in terms of primary +/- secondary diagnoses.

**Re-Admissions**

After an admission to hospital for a suspected seizure (or an attendance at ED) the aim of management should be to make an accurate diagnosis, manage urgent/emergency problems, optimise ongoing medical treatment (including referral to specialist outpatient services) and provide advice on self-care to reduce the risk of re-admission after discharge. Active epilepsy should trigger review by an epilepsy specialist to prevent further seizures and/or to refine the patients emergency care plan but this opportunity is often missed [15] [17] [32] [33] [20] and patients therefore remain at risk of further seizures and the associated morbidity [34], mortality [35] and health services costs [36] [37] of poorly controlled epilepsy. Our data show that 22.4% of patients had more than one

admission per year and that overall there was a 34% chance of readmission after a suspected seizure within 6 years which provides further evidence of potentially avoidable admissions and poor quality care. However, quantification of avoidable admissions using HES data is complicated by the diagnostic uncertainty and the difficulty distinguishing between those cases that are truly ambulatory care sensitive (e.g. sub-optimally treated patients with active epilepsy) and those which are not (e.g. intractable epilepsy, first epileptic seizures which don't meet the criteria for epilepsy [38], and many more). Some national performance indicators are predicated on the notion that good quality scheduled care can prevent all admissions for seizures [29] [39, 40] which makes their validity doubtful.

#### *Geographical Variability and Service Provision*

There is significant geographical variability in the directly standardised admission rates and there are four geographical areas (PCTs) whose mean rate throughout the study period is greater than 3SDs from the mean. This variability has not previously been reported in the published literature. Our research was not designed to investigate potential causes of the variability and the expected or optimal rate of hospital admissions per 100,000 is unknown. Factors which are likely to influence admission rates for suspected seizures are the prevalence of epilepsy, deprivation, the quality of ambulatory care and local practice in the emergency care system such as care pathways (including the accessibility of neurological advice) and ED discharge protocols. The four outliers ( $\geq 3$  SDs above the mean) are post-industrial areas in the north of England which is consistent with the hypothesis that deprivation is an important factor. Further research is required to investigate the causes of the variability demonstrated in this study. Comparison of rates of admissions for suspected seizures should be compared with all-cause admissions in future studies.

The study period for our data-set ends on 31/03/13 and is based on PCTs. CCGs came into being on 01/04/13 and although the geographical boundaries of many PCTs were identical to the CCGs that replaced them, some were different, and furthermore the initial configuration of CCGs has subsequently been changed. As such our PCT-based data is not directly comparable with current CCGs but this does not detract from the conclusion that there is significant geographical variability and commissioners may wish to review the up-to-date data.

#### *Under-diagnosis of Dissociative Seizures*

The EPIC 2 [15] study showed that 7.4% of all in-patient admissions in a UK centre which resulted from a 999 call for a suspected seizure were caused by dissociative seizures (DS) (ICD-10 code F44.5, also known as psychogenic nonepileptic seizures, PNES, or manifestations of non-epileptic attack disorder, NEAD) [15]. Based on this data we would estimate 22,250 ( $7.4\% \times 300,668$ ) (3,709 per year) admissions during the study period for DS but in our study the ICD-10 code for DS identified only 1,074 admissions in total (179/annum). Despite the fact that the nosology of DS is controversial and a number of different terms are used in the medical literature there is only one ICD-10 code for DS/PNES/NEAD, so it seems that miscoding is unlikely to be the cause of this discrepancy. The unexpectedly low number of cases coded as being admitted with DS adds to the evidence of under-diagnosis of DS by doctors in acute medical settings and of the misdiagnosis of DS as epileptic seizures [41] [42] [43] [44] [45]. In addition to case reports and case series of patients with DS receiving inappropriate emergency treatment for status epilepticus other indirect evidence for this problem comes from primary care studies demonstrating that non-expert diagnoses of epilepsy are regularly inaccurate and studies based in secondary care demonstrating that the mean diagnostic delay of DS is several years, with most patients with DS initially receiving treatment for epilepsy [46] [47] [48]. It may be that many patients who were admitted during the study period with a DS were actually coded using G40, G41 or R56.8. More research is required to accurately quantify the number of unplanned hospital admissions with DS, but as the management of dissociative seizures is

very different from that of epileptic seizures, this observation provokes concern that the ED management of psychogenic seizures may be suboptimal.

*A&E Data*

The HES A&E data dictionary uses a crude system of 58 diagnosis codes (at three-character level). Coding is done by individual clinicians many of who are junior doctors who have not had any training for this role. Using the HES A&E diagnosis code 241 (CNS epilepsy) for case ascertainment shows an average of 24,455 attendances per year that is significantly less than the number of admissions for suspected seizures based on the in-patient data. Many A&E attendances were classified as “unknown” or “diagnosis not classifiable” and it is not clear how the other two HES A&E neurology codes relate to the diagnosis of epilepsy. We conclude that HES A&E data is not of sufficient quality to make robust estimates of the number of attendances related to suspected seizures. The Emergency Care Data Set (ECDS) will supersede the current ED data and diagnosis codes will be based on the SNOMED-CT diagnostic codes [49] which may improve the quality of the data [50]. Until the issues with data quality in ED are resolved this will remain an important data-gap which undermines attempts to undertake high quality research, plan services and to evaluate service innovations.

*Implications for Clinical Care and Public Health in the United Kingdom and Internationally*

Epileptic seizures are usually self-limiting and in themselves are not medical emergencies but they account for a large number of emergency admissions many of which are potentially preventable. Important and potentially modifiable factors which give rise to unnecessary admissions are the quality of ambulatory care, advanced care planning and the configuration of emergency care pathways. Approximately 1 in 5 patients with epilepsy are having regular seizures which could be prevented with optimal treatment. Improvements in seizure freedom rates would in turn be likely to reduce the number of unscheduled admissions. Care planning for patients with intractable epilepsy in the form of an emergency care plan shared with relatives, friends and carers may reduce demand on emergency services. Emergency care pathways, designed to identify patients that can be safely managed without emergency attendance/admission to hospital, and to divert them to urgent but scheduled appointments in specialised services may improve care and reduce unnecessary admissions. Our research is based on data from the NHS in England and is inevitably context-specific, but research from other European countries shows similar problems with quality of ambulatory care for epilepsy, variability in services and high costs from potentially avoidable admissions. Prevalence of epilepsy and the incidence of seizures has much wider determinants that health-care provision. Alcohol, deprivation and comorbidities linked with seizures such as cerebrovascular disease, are all relevant and require a public-health approach to tackle them.

*Competing Interests and Acknowledgements*

This work was supported by UCB Pharma Ltd. through an educational grant the University of Sheffield (JMD, RAG, MR, JH) and consultancy fees to Health IQ (RM). UCB had no editorial control on the contents.

*Data Sharing Statement*

No unpublished data from this study is available.

*Contributorship Statement*

The idea for the study came from RAG. JMD was the Chief Investigator and he worked with all the authors to develop the protocol. JMD, JH and RJ took the lead with data analysis. JMD took the lead with writing the manuscript. All authors contributed to the manuscript and approved the final version.

Figure 1: Neurological diagnoses ranked by number of emergency hospital admissions between 31/04/07 and 31/03/13. Suspected seizures = G40 + G41 + R56.8.

Figure 2: Kaplan-Meier plots showing the time to first readmission after a suspected seizure when the first admission was for G40 + G41 + R56.8, G40, G41, R56.8. ICD-10 codes: G40 (epilepsy), G41 (status epilepticus) and R56.8 (other and unspecified convulsions).

Figure 3: Funnel plots showing the directly standardised emergency admission rate per 100,000 of the adult population 2007-2013 in each PCT. (A) G40 + G41 + R56.8, (B) G40, (C) R56.8. Each dot represents a PCT, the solid line shows the weighted mean for the standardised admission rate, and the dashed and dotted line shows 2 and 3 standard deviations from the mean respectively. ICD-10 codes: G40 (epilepsy), G41 (status epilepticus) and R56.8 (other and unspecified convulsions). There was not enough data to age-sex standardise the G41 diagnosis code.

## References

1. Banerjee, P.N., D. Filippi, and W. Allen Hauser, *The descriptive epidemiology of epilepsy-a review*. *Epilepsy Res*, 2009. **85**(1): p. 31-45.
2. Bardsley, M., et al., *Is secondary preventive care improving? Observational study of 10-year trends in emergency admissions for conditions amenable to ambulatory care*. *BMJ Open*, 2013. **3**: p. e002007.
3. Gupta, S., et al., *Understanding the burden of idiopathic generalized epilepsy in the United States, Europe, and Brazil: An analysis from the National Health and Wellness Survey*. *Epilepsy Behav*, 2016. **55**: p. 146-56.
4. Thurman, D.J., et al., *Health-care access among adults with epilepsy: The U.S. National Health Interview Survey, 2010 and 2013*. *Epilepsy Behav*, 2015.
5. Moran, N.F., et al., *Epilepsy in the United Kingdom: seizure frequency and severity, anti-epileptic drug utilization and impact on life in 1652 people with epilepsy*. *Seizure*, 2004. **13**(6): p. 425-33.
6. *Relationship Between Seizure Frequency and Costs and Quality of Life of Outpatients with Partial Epilepsy in France, Germany and the United Kingdom*.
7. *ILAE Commission on the Burden of Epilepsy, Subcommittee on the Economic Burden of Epilepsy: Final report 1998-2001*.
8. Sander, J.W., *The Use of Antiepileptic Drugs - Principles and Practice*. *Epilepsia*, 2004. **45**(Suppl. 6): p. 28-34.
9. Kwan, P. and M.J. Brodie, *Early identification of refractory epilepsy*. *The New England Journal of Medicine*, 2000. **342**(5): p. 319.
10. Association of British Neurologists, *Acute Neurology services survey 2014*. 2014.
11. Jon M Dickson, Peter A Scott, and Markus Reuber, *Epilepsy Service Provision in the National Health Service in England in 2012*. *Seizure*, 2015. **30**: p. 26-31.
12. Pearson, M., et al., *National Audit of Seizure Management in Hospitals (Clinical Report)*. 2012.
13. Pearson, M., et al., *National Audit of Seizure Management in Hospitals (Clinical Report)*. 2014.
14. Dickson, J.M., P.A. Scott, and M. Reuber, *Epilepsy service provision in the National Health Service in England in 2012*. *Seizure*, 2015. **30**: p. 26-31.
15. Dickson, J., et al., *Cross-sectional study of the hospital management of adult patients with a suspected seizure (EPIC2)*. *BMJ Open*, 2017. **7**: p. e015696.
16. Office for National Statistics. *Time series: England population mid-year estimate*. 15/02/18]; Available from: [www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/timeseries/enpop/pop](http://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/timeseries/enpop/pop).
17. Dixon, P., et al., *National Audit of Seizure management in Hospitals (NASH): results of the national audit of epilepsy in the UK*. *BMJ Open*, 2015. **5**: p. e007325.
18. Tian, Y., A. Dixon, and H. Gao, *Emergency hospital admissions for ambulatory care-sensitive conditions: identifying the potential for reductions*, in *Data Briefing*. 2012, The King's Fund.
19. The NHS Information Centre, *CCG outcomes indicator set - emergency admissions*. 2013.
20. Malmgren, K., M. Reuber, and R. Appleton, *Differential diagnosis of epilepsy*, in *Oxford Textbook of Epilepsy and Epileptic Seizures 2013*, Oxford University Press.
21. Fund., T.K. *The new NHS: clinical commissioning groups*. 04/01/18]; Available from: <https://www.kingsfund.org.uk/projects/new-nhs/clinical-commissioning-groups>.
22. Health and Social Care Information Centre. *HES A&E Data Dictionary*. January 2016]; Available from: <http://www.hscic.gov.uk/article/3966/HES-AE-Data-Dictionary>.
23. Office for National Statistics. *Primary Care Organisations Mid-Year Population Estimates, Mid 2011 (Census Based)*. Available from: <http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-297507>.



24. Spiegelhalter, D., *Funnel plots for comparing institutional performance*. . Stat Med, 2005. **24**: p. 1185-202.
25. Spiegelhalter, D.J., *Handling over-dispersion of performance indicators*. Qual Saf Health Care, 2005. **14**(5): p. 347-51.
26. Wasserman, D. and M. Herskovitz, *Epileptic vs psychogenic nonepileptic seizures: a video-based survey*. Epilepsy and Behaviour, 2017. **73**: p. 42-45.
27. Jackson, A., L. Teo, and U. Seneviratne, *Challenges in the first seizure clinic for adult patients with epilepsy*. Epileptic Disorders, 2016. **18**: p. 305-314.
28. Grainger, R., et al., *Referral patterns after a seizure admission in an English region: an opportunity for effective intervention? An observational study of routine hospital data*. BMJ Open, 2016. **6**(1): p. e010100.
29. NHS England, *The NHS Atlas of Variation in Healthcare*. 2015.
30. Burns, E.M., et al., *Systematic review of discharge coding accuracy*. J Public Health (Oxf), 2012. **34**(1): p. 138-48.
31. Jette, N., et al., *How accurate is ICD coding for epilepsy?* Epilepsia, 2010. **51**(1): p. 62-9.
32. National Institute of Clinical Excellence, *The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care*. 2012.
33. National Institute for Health and Care Excellence, *Transient loss of consciousness ('blackouts') management in adults and young people*. 2010.
34. Baker, G., A. Jacoboy, and B. D., *Quality of life of people with epilepsy: a European study*. Epilepsia, 1997. **38**: p. 353-362.
35. Lhatoo, S., et al., *Mortality in Epilepsy in the First 11 to 14 Years after Diagnosis: Multivariate Analysis of a Long-Term, Prospective, Population-Based Cohort*. Annals of Neurology, 2001. **2001**: p. 336-344.
36. Manjunath, R., et al., *Burden of uncontrolled epilepsy in patients requiring an emergency room visit or hospitalization*. Neurology, 2012. **79**: p. 1908-1916.
37. Galarraga, J., R. Mutter, and J. Pines, *Costs associated with ambulatory care sensitive conditions across hospital-based settings*. Academic Emergency Medicine, 2015. **22**: p. 172-181.
38. Fisher, R.S., et al., *ILAE official report: a practical clinical definition of epilepsy*. Epilepsia, 2014. **55**(4): p. 475-82.
39. NHS England, *CCG Outcomes Indicator Set 2014/15: technical guidance*. December 2013.
40. Department of Health, *The NHS Outcomes Framework 2015/16*. 2014.
41. Reuber, M., et al., *Clinical significance of recurrent psychogenic nonepileptic seizure status*. Journal of Neurology, 2003. **250**(11): p. 1355-1362.
42. Reuber, M., et al., *Failure to recognize psychogenic nonepileptic seizures may cause death*. Neurology, 2004. **62**(5): p. 834-835.
43. Gunatilake, S., H. De Silva, and G. Ranasinghe, *Twenty-seven venous cutdowns to treat pseudostatus epilepticus*. 1997. **6**(1): p. 71-72.
44. Howell, S., L. Owen, and D. Chadwick, *Pseudostatus epilepticus*. Quarterly Journal of Medicine, 1989. **71**(266): p. 507-519.
45. Holtkamp, M., et al., *Diagnosis of psychogenic nonepileptic status epilepticus in the emergency setting*. Neurology, 2006. **66**(11): p. 1727-1729.
46. Leach, J.P., et al., *Epilepsy in the UK: misdiagnosis, mistreatment, and undertreatment? The Wrexham area epilepsy project*. Seizure, 2005. **14**(7): p. 514-20.
47. Reuber, M., et al., *Diagnostic delay in psychogenic nonepileptic seizures*. Neurology, 2002. **2002**(58): p. 493-495.
48. Kerr, W., et al., *Diagnostic delay in psychogenic seizures and the association with anti-seizure medication trials*. . Seizure, 2016. **40**: p. 123-126.
49. SNOMED International. *SNOMED CT*. [Accessed 04/01/18]; Available from: <https://www.snomed.org/snomed-ct>.

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

50. Dickson, J., S. Mason, and A. Bailey, *Emergency department diagnostic codes: useful data?* Emergency Medicine Journal, 2017. **34**: p. 627.

For peer review only

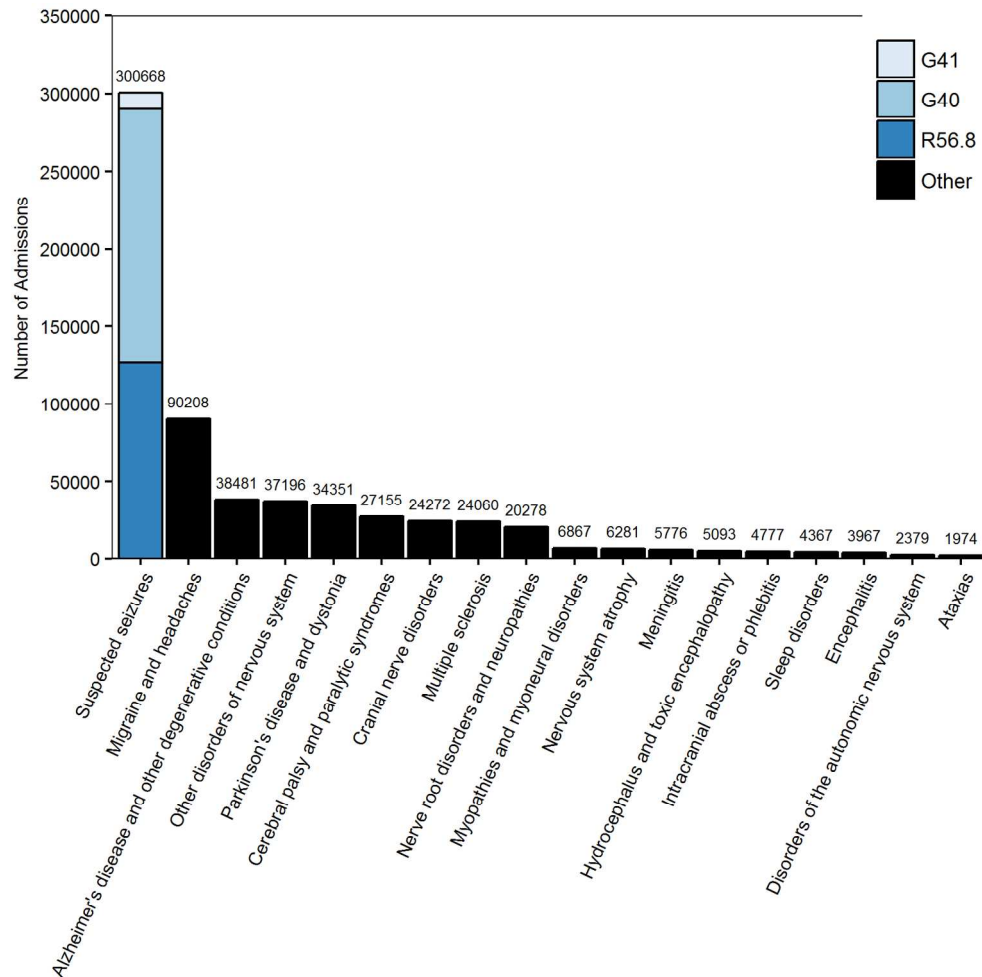


Figure 1: Neurological diagnoses ranked by number of emergency hospital admissions between 31/04/07 and 31/03/13. Suspected seizures = G40 + G41 + R56.8.

152x152mm (300 x 300 DPI)



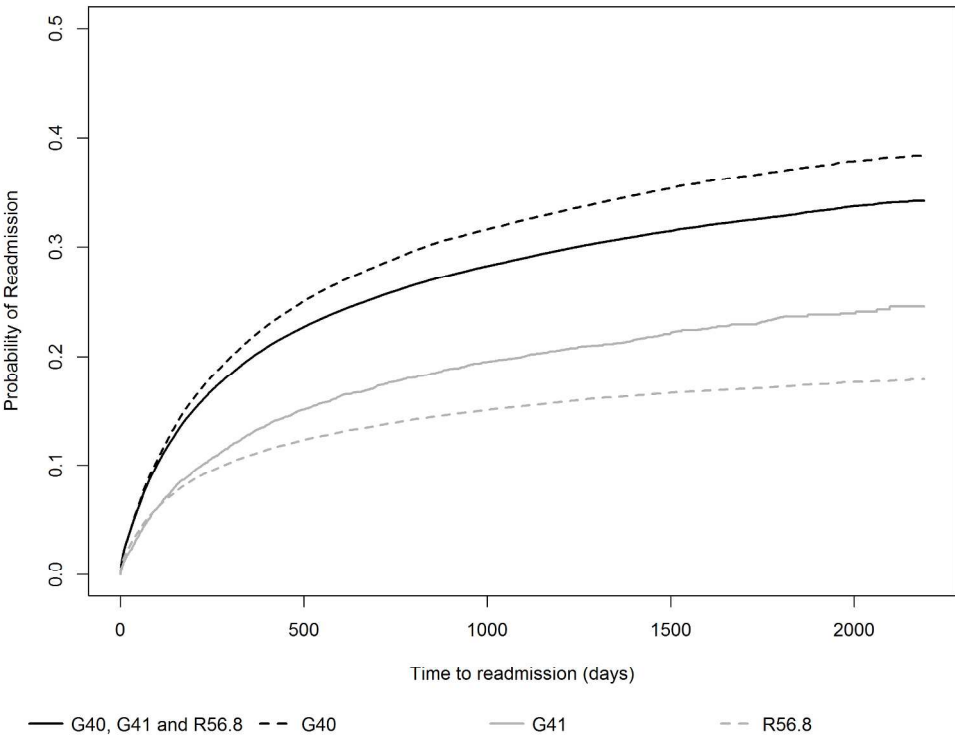


Figure 2: Kaplan-Meier plots showing the time to first readmission after a suspected seizure when the first admission was for G40 + G41 + R56.8, G40, G41, R56.8. ICD-10 codes: G40 (epilepsy), G41 (status epilepticus) and R56.8 (other and unspecified convulsions).

228x177mm (300 x 300 DPI)

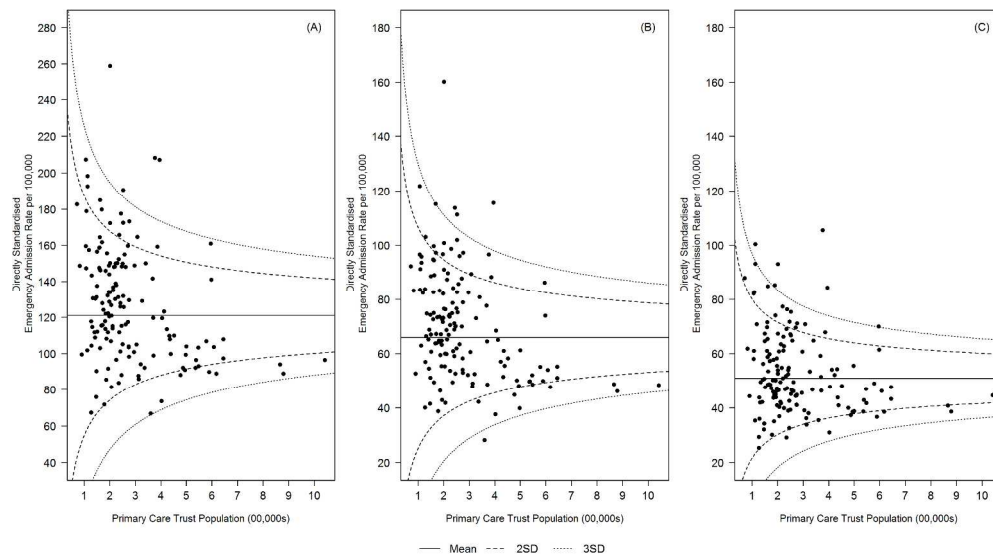


Figure 3: Funnel plots showing the directly standardised emergency admission rate per 100,000 of the adult population 2007-2013 in each PCT. (A) G40 + G41 + R56.8, (B) G40, (C) R56.8. Each dot represents a PCT, the solid line shows the weighted mean for the standardised admission rate, and the dashed and dotted line shows 2 and 3 standard deviations from the mean respectively. ICD-10 codes: G40 (epilepsy), G41 (status epilepticus) and R56.8 (other and unspecified convulsions). There was not enough data to age-sex standardise the G41 diagnosis code.

304x177mm (300 x 300 DPI)

PCT CODE	PCT NAME	Rate Y1	Rate Y2	Rate Y3	Rate Y4	Rate Y5	Rate Y6	Rate All
5 E1	STOCKTON-ON-TEES TEACHING PCT	129.66	136.59	147.01	139.65	140.41	131.28	137.43
5A3	SOUTH GLOUCESTERSHIRE PCT	73.21	88.33	82.82	83.29	87.12	73.39	81.36
5A4	HAVERING PCT	100.52	94.37	120.09	122.63	122.21	89.93	108.29
5A5	KINGSTON	67.25	48.45	64.10	73.96	81.04	69.66	67.41
5A7	BROMLEY PCT	80.90	125.57	109.69	102.18	88.63	100.45	101.24
5A8	NHS GREENWICH	80.75	88.28	88.80	98.33	95.17	99.28	91.77
5A9	BARNET PRIMARY CARE TRUST	70.47	113.05	113.10	111.81	106.45	108.84	103.95
5AT	HILLINGDON PCT	111.80	101.00	124.18	115.34	105.00	126.16	113.91
5C1	ENFIELD PCT	64.45	84.92	95.53	86.72	71.88	99.15	83.78
5C2	BARKING AND DAGENHAM PCT	119.75	114.87	124.15	162.35	125.39	136.75	130.54
5C3	CITY AND HACKNEY TEACHING PCT	141.32	132.33	122.64	125.36	118.13	132.12	128.65
5C4	TOWER HAMLETS PRIMARY CARE TEAM	163.60	170.51	150.38	150.36	146.43	119.65	150.15
5C5	NEWHAM PRIMARY CARE TEAM	117.27	128.77	121.46	148.22	128.50	143.49	131.28
5C9	HARINGEY PCT	135.47	104.69	111.27	115.58	130.95	125.21	120.53
5CN	NHS HEREFORDSHIRE	82.31	94.12	89.42	103.61	94.64	77.41	90.25
5CQ	MILTON KEYNES PCT	101.74	121.76	103.71	123.29	122.16	98.31	111.83
5D7	NEWCASTLE PCT	145.13	128.02	136.25	137.09	141.20	139.71	137.90
5D8	NORTH TYNESIDE PCT	175.56	150.78	127.84	151.21	145.17	130.03	146.76
5D9	HARTLEPOOL PCT	148.91	138.08	207.39	175.41	203.56	222.55	182.65
5EF	NORTH LINCOLNSHIRE PCT	124.11	108.69	158.66	139.06	164.36	165.41	143.38
5EM	NOTTINGHAM CITY PCT	124.48	129.71	127.88	133.35	121.41	119.49	126.05
5ET	BASSETLAW	98.22	94.36	105.86	89.23	112.22	97.17	99.51
5F1	PLYMOUTH PRIMARY CARE TRUST	117.32	118.06	134.07	111.79	136.63	142.88	126.79
5F5	SALFORD PCT	152.29	131.29	161.18	148.40	140.36	142.22	145.96
5F7	STOCKPORT PCT	123.46	147.94	142.55	150.51	126.57	142.37	138.90
5FE	PORTSMOUTH CITY TEACHING PCT	153.70	144.34	143.41	155.46	155.43	125.47	146.30
5FL	BATH AND NORTH EAST SOMERSET PCT	122.26	122.07	96.23	95.94	106.49	109.84	108.80
5GC	LUTON PCT	98.89	104.94	97.83	103.08	129.70	138.30	112.12
5H1	HAMMERSMITH & FULHAM PCT	168.93	142.77	167.75	159.95	153.19	146.56	156.53
5H8	ROTHERHAM PCT	123.03	131.06	120.44	136.02	163.13	130.42	134.02
5HG	ASHTON LEIGH AND WIGAN PCT	135.72	149.07	149.97	155.71	156.39	152.21	149.85
5HP	BLACKPOOL PCT	172.44	169.54	192.81	186.40	229.81	204.59	192.60
5HQ	BOLTON PCT	142.81	135.52	123.90	135.49	118.28	154.04	135.01
5HX	EALING PCT	136.15	133.76	145.93	143.20	165.51	164.19	148.12
5HY	HOUNSLOW PCT	123.62	133.13	130.64	146.33	143.22	127.44	134.06
5J2	WARRINGTON PCT	133.10	132.08	162.74	137.10	171.79	149.00	147.64
5J4	KNOWSLEY	238.75	207.17	197.61	192.27	171.49	182.80	198.35
5J5	OLDHAM PRIMARY CARE TRUST	175.18	179.00	169.40	189.20	216.26	149.22	179.71
5J6	CALDERDALE PCT	158.79	158.67	159.96	164.06	156.03	154.62	158.69
5J9	DARLINGTON PCT	149.36	162.28	132.87	180.27	151.32	116.06	148.69
5JE	BARNESLEY PCT	93.45	124.23	125.78	116.64	109.26	111.95	113.55
5JX	BURY PRIMARY CARE TRUST	127.82	135.91	106.84	158.44	135.17	117.77	130.33
5K3	SWINDON PCT	88.66	114.78	122.82	116.85	120.12	129.71	115.49
5K5	BRENT PCT	122.83	131.28	125.79	129.21	112.47	145.62	127.87
5K6	HARROW PCT	66.20	82.41	79.22	97.69	87.64	100.45	85.61
5K7	CAMDEN PRIMARY CARE TRUST	131.27	128.29	136.51	90.72	102.71	117.91	117.90
5K8	ISLINGTON PRIMARY CARE TRUST	142.64	170.43	195.60	157.63	158.22	145.52	161.67
5K9	CROYDON PRIMARY CARE TRUST	114.24	116.53	139.22	129.55	136.51	141.17	129.53
5KF	GATESHEAD PRIMARY CARE TRUST	145.27	171.59	168.88	148.79	168.36	149.88	158.80
5KG	SOUTH TYNESIDE PCT	139.59	151.25	151.19	191.47	161.01	150.18	157.45
5KL	SUNDERLAND TEACHING PRIMARY CARE TRUST	143.91	137.09	156.69	118.23	113.43	111.87	130.21
5KM	MIDDLESBROUGH PCT	195.28	223.36	204.92	198.60	219.14	202.55	207.31
5L1	SOUTHAMPTON CITY PCT	107.12	168.37	160.32	161.16	149.22	187.45	155.61
5L3	NHS MEDWAY	117.07	99.79	109.33	107.43	102.05	105.71	106.90
5LA	KENSINGTON AND CHELSEA PCT	99.10	116.45	112.81	114.74	134.81	110.07	114.66
5LC	WESTMINSTER PCT	126.99	123.35	120.79	120.78	130.65	109.34	121.98
5LD	LAMBETH PCT	180.64	139.72	175.87	194.79	171.32	202.89	177.54
5LE	SOUTHWARK PCT	142.34	140.35	134.14	182.78	148.38	153.72	150.28
5LF	LEWISHAM PCT	144.60	125.42	145.10	130.23	125.99	149.48	136.80
5LG	WANDSWORTH PCT	126.26	145.94	129.99	119.30	135.35	134.42	131.88
5LH	TAMESIDE AND GLOSSOP PRIMARY CARE TRUST	131.53	117.96	143.35	171.11	165.76	162.95	148.78
5LQ	BRIGHTON AND HOVE CITY TEACHING PCT	128.94	158.53	137.92	174.85	158.49	141.89	150.10
5M1	SOUTH BIRMINGHAM PCT	159.69	171.30	170.40	184.03	182.46	171.34	173.20
5M2	SHROPSHIRE COUNTY PRIMARY CARE TRUST	79.34	78.45	86.90	100.18	92.85	91.19	88.15
5M3	WALSALL TEACHING PCT	126.44	130.20	127.38	121.19	113.32	107.19	120.95
5M6	RICHMOND & TWICKENHAM	69.77	55.91	61.07	80.50	92.11	95.98	75.89
5M7	SUTTON & MERTON PCT	102.56	110.36	109.77	106.26	97.78	103.10	104.97
5M8	NORTH SOMERSET PCT	85.54	100.18	108.40	118.15	106.06	99.57	102.98
5MD	COVENTRY PRIMARY CARE TRUST	125.31	140.54	145.69	148.42	162.01	168.12	148.35
5MK	TELFORD & WREKIN PRIMARY CARE TRUST	90.02	94.56	122.95	92.18	114.20	112.43	104.39
5MV	WOLVERHAMPTON CITY PRIMARY CARE TRUST	121.54	103.81	134.50	117.15	132.10	123.70	122.13
5MX	HEART OF BIRMINGHAM TEACHING PCT	139.64	138.89	155.95	178.63	137.48	138.15	148.12
5N1	LEEDS PCT	140.76	170.49	162.08	162.65	173.56	156.50	161.01
5N2	KIRKLEES PCT	112.06	135.66	131.94	147.37	141.08	106.53	129.11

1	5N3	WAKEFIELD DISTRICT PCT	159.03	153.72	174.82	161.89	142.71	137.90	155.01
2	5N4	SHEFFIELD PCT	85.49	88.07	105.83	104.61	107.30	108.00	99.88
3	5N5	DONCASTER PCT	103.27	85.69	109.60	115.21	136.73	119.85	111.72
4	5N6	DERBYSHIRE COUNTY PCT	83.28	86.44	92.84	92.97	98.94	84.38	89.81
5	5N7	DERBY CITY PCT	105.14	124.38	115.30	127.32	136.29	122.53	121.83
6	5N8	NHS NOTTINGHAMSHIRE COUNTY	86.21	96.62	95.97	87.70	98.27	87.87	92.11
7	5N9	LINCOLNSHIRE PCT	90.33	98.68	103.91	109.39	117.55	121.13	106.83
8	5NA	REDBRIDGE PCT	110.12	119.98	125.64	122.08	103.53	109.86	115.20
9	5NC	WALTHAM FOREST PCT	111.79	125.26	154.38	161.43	153.85	156.64	143.89
10	5ND	COUNTY DURHAM PCT	106.95	117.06	122.06	134.56	130.87	128.07	123.26
11	5NE	CUMBRIA TEACHING PCT	128.19	124.64	121.12	117.07	116.22	109.81	119.51
12	5NF	NORTH LANCASHIRE TEACHING PCT	99.58	106.44	125.54	124.95	116.44	123.38	116.05
13	5NG	CENTRAL LANCS PCT	112.62	116.74	119.10	129.88	115.52	124.70	119.76
14	5NH	EAST LANCASHIRE TEACHING PCT	140.95	117.57	157.57	162.52	159.26	154.85	148.78
15	5NJ	SEFTON PCT	197.04	132.99	149.26	145.29	117.47	147.48	148.25
16	5NK	WIRRAL PCT	182.27	179.53	172.71	201.85	198.35	208.95	190.61
17	5NL	LIVERPOOL PCT	221.47	221.68	199.18	214.04	208.77	184.19	208.22
18	5NM	HALTON & ST HELENS PCT	139.79	172.26	156.64	170.58	176.31	178.44	165.67
19	5NN	WESTERN CHESHIRE PCT	122.36	138.36	160.12	142.43	116.65	112.87	132.13
20	5NP	CENTRAL AND EASTERN CHESHIRE PCT	118.29	151.78	169.47	169.06	127.91	113.54	141.67
21	5NQ	HEYWOOD MIDDLETON & ROCHDALE PCT	149.85	166.30	156.41	180.94	166.74	166.23	164.41
22	5NR	TRAFFORD PCT	110.74	118.93	131.68	122.72	138.56	122.80	124.24
23	5NT	MANCHESTER PCT	201.31	207.09	187.70	211.74	214.17	220.78	207.13
24	5NV	NORTH YORKSHIRE AND YORK PCT	90.96	94.12	101.95	100.01	102.39	94.43	97.31
25	5NW	EAST RIDING OF YORKSHIRE PCT	114.17	124.81	110.80	138.35	118.07	98.04	117.37
26	5NX	HULL TEACHING PCT	241.01	253.06	267.93	265.61	266.75	259.76	259.02
27	5NY	BRADFORD & AIREDALE PCT	148.08	165.34	157.89	169.81	169.87	144.75	159.29
28	5P1	SOUTH EAST ESSEX PCT	98.24	102.06	97.80	108.26	106.68	107.86	103.48
29	5P2	BEDFORDSHIRE PCT	86.22	93.55	94.34	96.33	96.98	97.17	94.10
30	5P5	SURREY PCT	80.67	90.60	92.57	91.49	89.52	89.18	89.00
31	5P6	WEST SUSSEX PCT	93.45	107.32	113.23	114.08	114.81	104.84	107.96
32	5P7	EAST SUSSEX DOWNS & WEALD PCT	97.36	100.97	91.31	96.44	89.36	114.55	98.33
33	5P8	HASTINGS & ROTHER PCT	148.50	139.08	149.15	142.16	108.40	99.70	131.17
34	5P9	NHS WEST KENT	98.65	102.34	103.88	102.28	106.01	106.40	103.26
35	5PA	LEICESTERSHIRE COUNTY & RUTLAND PCT	94.01	88.73	85.02	93.97	94.92	101.39	93.01
36	5PC	LEICESTER CITY PCT	178.49	167.97	174.86	173.85	181.37	158.26	172.47
37	5PD	NORTHAMPTONSHIRE PCT	80.55	100.10	95.82	100.04	98.69	103.81	96.50
38	5PE	NHS DUDLEY	99.62	96.40	110.46	133.36	134.91	117.24	115.33
39	5PF	SANDWELL PRIMARY CARE TRUST	157.01	149.68	138.64	160.49	159.34	148.93	152.35
40	5PG	BIRMINGHAM EAST AND NORTH PCT	152.18	163.95	174.54	186.94	154.28	155.80	164.61
41	5PH	NORTH STAFFORDSHIRE PCT	107.27	121.01	124.77	117.93	100.54	122.75	115.71
42	5PJ	STOKE ON TRENT PCT	163.92	150.48	182.22	164.52	181.56	191.35	172.34
43	5PK	SOUTH STAFFORDSHIRE PRIMARY CARE TRUST	93.83	96.90	103.67	105.69	109.12	114.55	103.96
44	5PL	NHS WORCESTERSHIRE	95.82	112.25	117.63	105.51	101.57	126.58	109.89
45	5PM	WARWICKSHIRE PCT	94.87	94.66	111.07	129.61	104.05	113.08	107.89
46	5PN	PETERBOROUGH PCT	113.44	122.83	116.71	104.66	118.20	95.01	111.81
47	5PP	CAMBRIDGESHIRE PCT	79.20	84.00	93.51	96.47	100.95	91.66	90.97
48	5PQ	NORFOLK PRIMARY CARE TRUST	87.48	84.70	83.37	87.38	95.10	95.77	88.97
49	5PR	GREAT YARMOUTH AND WAVENEY PCT	111.14	122.89	113.88	121.77	147.19	150.07	127.82
50	5PT	SUFFOLK PCT	79.08	88.16	93.11	98.85	97.23	96.04	92.08
51	5PV	WEST ESSEX PCT	93.05	77.56	93.83	107.21	113.62	94.60	96.65
52	5PW	NORTH EAST ESSEX PCT	87.79	84.96	116.04	101.69	120.40	120.24	105.19
53	5PX	MID ESSEX PCT	82.08	122.96	119.77	103.47	88.04	89.39	100.95
54	5PY	SOUTH WEST ESSEX PCT	86.82	83.28	82.95	85.21	86.72	90.51	85.92
55	5QA	NHS EASTERN & COASTAL KENT	132.38	132.82	134.03	144.30	152.08	150.08	140.95
56	5QC	HAMPSHIRE PRIMARY CARE TRUST	81.16	93.22	101.96	99.37	101.02	101.52	96.38
57	5QD	BUCKINGHAMSHIRE PCT	76.04	78.68	69.36	64.33	78.94	74.15	73.58
58	5QE	OXFORDSHIRE PRIMARY CARE TRUST	97.18	102.20	109.93	91.21	95.80	99.97	99.38
59	5QF	BERKSHIRE WEST PRIMARY CARE TRUST	61.84	63.97	67.50	68.61	66.68	72.46	66.84
60	5QG	BERKSHIRE EAST PRIMARY CARE TRUST	67.94	82.42	79.73	87.09	106.79	102.57	87.76
	5QH	GLOUCESTERSHIRE PCT	67.93	77.30	77.54	99.18	107.96	99.24	88.19
	5QJ	BRISTOL PCT	145.77	158.63	153.99	146.35	154.73	140.78	150.04
	5QK	WILTSHIRE PCT	90.35	96.90	95.36	95.34	103.96	111.77	98.95
	5QL	SOMERSET PRIMARY CARE TRUST	86.78	108.93	116.83	115.51	125.30	126.91	113.38
	5QM	DORSET PRIMARY CARE TRUST	80.80	75.37	88.75	87.30	110.26	110.32	92.13
	5QN	BOURNEMOUTH AND POOLE TEACHING PCT	136.15	140.44	159.23	185.88	172.48	164.26	159.74
	5QP	CORNWALL AND ISLES OF SCILLY PCT	115.23	105.72	103.19	109.52	111.54	112.98	109.69
	5QQ	DEVON PRIMARY CARE TRUST	107.39	97.62	95.04	103.93	106.75	110.78	103.58
	5QR	REDCAR AND CLEVELAND PCT	167.53	148.40	137.60	131.31	157.97	141.06	147.31
	5QT	ISLE OF WIGHT NHS PCT	61.77	105.91	100.11	130.41	107.42	105.05	101.78
	5QV	HERTFORDSHIRE PCT	80.23	82.68	91.78	96.45	105.92	106.49	93.92
	5QW	SOLIHULL PCT	213.26	198.25	169.40	199.13	159.04	170.58	184.94
	TAC	NORTHUMBERLAND CARE TRUST	129.24	134.05	104.36	113.49	142.63	130.17	125.66
	TAK	NHS BEXLEY	65.29	70.62	65.29	68.93	64.34	95.93	71.74
	TAL	TORBAY CARE TRUST	143.72	167.82	134.41	155.18	176.78	179.19	159.52

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

TAN	NORTH EAST LINCOLNSHIRE CARE TRUST PLUS	108.75	98.22	120.78	116.65	148.62	113.04	117.68
TAP	BLACKBURN WITH DARWEN PCT	145.44	145.57	183.70	202.98	193.03	202.34	178.85

For peer review only

Diagnosis Group Label	ICD-10	ICD10 Description
Migraine and headaches	G43	Migraine
	G44	Other headache syndromes
Alzheimer's disease and....	G30	Alzheimer's disease
	G31	Other degenerative diseases of nervous system, not elsewhere classified
	G32	Other degenerative disorders of nervous system in diseases classified elsewhere
Other disorders of nervous system	G93	Other disorders of brain
	G94	Other disorders of brain in diseases classified elsewhere
	G95	Other diseases of spinal cord
	G96	Other disorders of central nervous system
	G97	Post-procedural disorders of nervous system, not elsewhere classified
	G98	Other disorders of nervous system, not elsewhere classified
	G99	Other disorders of nervous system in diseases classified elsewhere
Parkinson's disease and dystonia	G20	Parkinson's disease
	G21	Secondary parkinsonism
	G23	Other degenerative diseases of basal ganglia
	G24	Dystonia
	G25	Other extrapyramidal and movement disorders
Cerebral palsy and paralytic syndromes	G80	Cerebral palsy
	G81	Hemiplegia
	G82	Paraplegia and tetraplegia
	G83	Other paralytic syndromes
Cranial Nerve Disorders	G50	Disorders of trigeminal nerve
	G51	Facial nerve disorders
	G52	Disorders of other cranial nerves
	G53	Cranial nerve disorders in diseases classified elsewhere
Multiple sclerosis	G35	Multiple sclerosis
	G36	Other acute disseminated demyelination
	G37	Other demyelinating diseases of central nervous system
Nerve Root Disorders and neuropathies	G54	Nerve root and plexus disorders
	G55	Nerve root and plexus compressions in diseases classified elsewhere
	G56	Mono-neuropathies of upper limb

	G57	Mono-neuropathies of lower limb
	G58	Other mono-neuropathies
	G59	Mono-neuropathy in diseases classified elsewhere
	G60	Hereditary and idiopathic neuropathy
	G61	Inflammatory polyneuropathy
	G62	Other polyneuropathies
	G63	Polyneuropathy in diseases classified elsewhere
	G64	Other disorders of peripheral nervous system
Myopathies and myoneural disorders	G70	Myasthenia gravis and other myo-neural disorders
	G71	Primary disorders of muscles
	G72	Other myopathies
	G73	Disorders of myo-neural junction and muscle in diseases classified elsewhere
Nervous system atrophy	G12	Spinal muscular atrophy and related syndromes
	G13	Systemic atrophies primarily affecting central nervous system in diseases classified elsewhere
	G14	Post-polio syndrome
Huntington's disease	G10	Huntington's disease
Meningitis	G00	Bacterial meningitis, not elsewhere classified
	G01	Meningitis in bacterial diseases classified elsewhere
	G02	Meningitis in other infectious and parasitic diseases classified elsewhere
	G03	Meningitis due to other and unspecified causes
Hydrocephalus and toxic encephalopathy	G91	Hydrocephalus
	G92	Toxic encephalopathy
Intra-cranial abscess or phlebitis	G06	Intracranial and intra-spinal abscess and granuloma
	G07	Intracranial and intra-spinal abscess and granuloma in diseases classified elsewhere
	G08	Intracranial and intra-spinal phlebitis and thrombophlebitis
Sleep disorders	G47	Sleep disorders
Encephalitis	G04	Encephalitis, myelitis and encephalomyelitis
	G05	Encephalitis, myelitis and encephalomyelitis in diseases classified elsewhere
Disorders of the autonomic nervous system	G90	Disorders of autonomic nervous system
Ataxias	G11	Hereditary ataxia



The RECORD statement – checklist of items, extended from the STROBE statement, that should be reported in observational studies using routinely collected health data.

Item No.	STROBE items	Location in manuscript where items are reported	RECORD items	Location in manuscript where items are reported
<b>Title and abstract</b>				
1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found	pgs 1-2	RECORD 1.1: The type of data used should be specified in the title or abstract. When possible, the name of the databases used should be included.  RECORD 1.2: If applicable, the geographic region and timeframe within which the study took place should be reported in the title or abstract.  RECORD 1.3: If linkage between databases was conducted for the study, this should be clearly stated in the title or abstract.	pg 2  pg 2  11A
<b>Introduction</b>				
2	Explain the scientific background and rationale for the investigation being reported	pg 4		pg 4
3	State specific objectives, including any prespecified hypotheses	pg 4		pg 4
<b>Methods</b>				
4	Present key elements of study design early in the paper			pgs 4-6
5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection			pgs 4-6
6	(a) <i>Cohort study</i> - Give the		RECORD 6.1: The methods of study	

		<p>eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up</p> <p><i>Case-control study</i> - Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls</p> <p><i>Cross-sectional study</i> - Give the eligibility criteria, and the sources and methods of selection of participants</p> <p>(b) <i>Cohort study</i> - For matched studies, give matching criteria and number of exposed and unexposed</p> <p><i>Case-control study</i> - For matched studies, give matching criteria and the number of controls per case</p>	<p>§ 4-6</p>	<p>population selection (such as codes or algorithms used to identify subjects) should be listed in detail. If this is not possible, an explanation should be provided.</p> <p>RECORD 6.2: Any validation studies of the codes or algorithms used to select the population should be referenced. If validation was conducted for this study and not published elsewhere, detailed methods and results should be provided.</p> <p>RECORD 6.3: If the study involved linkage of databases, consider use of a flow diagram or other graphical display to demonstrate the data linkage process, including the number of individuals with linked data at each stage.</p>	<p>§ 4-6</p> <p>N/A</p> <p>N/A</p>
Variables	7	<p>Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable.</p>		<p>RECORD 7.1: A complete list of codes and algorithms used to classify exposures, outcomes, confounders, and effect modifiers should be provided. If these cannot be reported, an explanation should be provided.</p>	<p>§ 4-6</p>
Data sources/ measurement	8	<p>For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group</p>			<p>§ 4-6</p>
Bias	9	<p>Describe any efforts to address potential sources of bias</p>			<p>N/A</p>

Study size	10	Explain how the study size was arrived at			NA
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why			pg 4-6
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) <i>Cohort study</i> - If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> - If applicable, explain how matching of cases and controls was addressed <i>Cross-sectional study</i> - If applicable, describe analytical methods taking account of sampling strategy (e) Describe any sensitivity analyses			pg 4-6
Data access and cleaning methods		..		RECORD 12.1: Authors should describe the extent to which the investigators had access to the database population used to create the study population.  RECORD 12.2: Authors should provide information on the data cleaning methods used in the study.  RECORD 12.3: State whether the	pg 4-6
Linkage		..			

					study included person-level, institutional-level, or other data linkage across two or more databases. The methods of linkage and methods of linkage quality evaluation should be provided.	11A
<b>Results</b>						
Participants	13	(a) Report the numbers of individuals at each stage of the study ( <i>e.g.</i> , numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed) (b) Give reasons for non-participation at each stage. (c) Consider use of a flow diagram	Fig 6-7	RECORD 13.1: Describe in detail the selection of the persons included in the study ( <i>i.e.</i> , study population selection) including filtering based on data quality, data availability and linkage. The selection of included persons can be described in the text and/or by means of the study flow diagram.	Fig 6-7	
Descriptive data	14	(a) Give characteristics of study participants ( <i>e.g.</i> , demographic, clinical, social) and information on exposures and potential confounders (b) Indicate the number of participants with missing data for each variable of interest (c) <i>Cohort study</i> - summarise follow-up time ( <i>e.g.</i> , average and total amount) <i>Cohort study</i> - Report numbers of outcome events or summary measures over time <i>Case-control study</i> - Report numbers in each exposure category, or summary measures of exposure <i>Cross-sectional study</i> - Report numbers of outcome events or	Fig 6-7			
Outcome data	15		Fig 6-7			

Main results	16	summary measures (a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	Pg 6-7		
Other analyses	17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses	Pg 6-7		
<b>Discussion</b>					
Key results	18	Summarise key results with reference to study objectives	Pg 7-9		
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	Pg 7-9 Pg 3		RECORD 19.1: Discuss the implications of using data that were not created or collected to answer the specific research question(s). Include discussion of misclassification bias, unmeasured confounding, missing data, and changing eligibility over time, as they pertain to the study being reported.
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Pg 7-9		

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

Generalisability	21	Discuss the generalisability (external validity) of the study results	Fig 7-a		
Other Information					
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	Fig 9		
Accessibility of protocol, raw data, and programming code		..		RECORD 22.1: Authors should provide information on how to access any supplemental information such as the study protocol, raw data, or programming code.	Fig 9

\*Reference: Benchimol EI, Smeeth L, Guttman A, Harron K, Moher D, Petersen I, Sørensen HT, von Elm E, Langan SM, the RECORD Working Committee. The REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) Statement. *PLoS Medicine* 2015; in press.

\*Checklist is protected under Creative Commons Attribution (CC BY) license.

# BMJ Open

## Emergency Hospital Care for Adults with Suspected Seizures in the NHS in England 2007-2013: A Cross-Sectional Study

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2018-023352.R2
Article Type:	Research
Date Submitted by the Author:	26-Jul-2018
Complete List of Authors:	Dickson, Jon; The University of Sheffield , The Academic Unit of Primary Medical Care Jacques, Richard; University of Sheffield, SchARR Reuber, Markus; The University of Sheffield Hick, Julian; Baslow Health Centre Campbell, Michael; University of Sheffield, SchARR Morley, Rebeka; Health IQ Grünewald, Richard; Sheffield Teaching Hospitals NHS Foundation Trust, Department of Neurosciences
<b>Primary Subject Heading</b>:	Neurology
Secondary Subject Heading:	Emergency medicine, Epidemiology, Health services research
Keywords:	Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Neurology < INTERNAL MEDICINE, Epilepsy < NEUROLOGY

SCHOLARONE™  
Manuscripts



# Emergency Hospital Care for Adults with Suspected Seizures in the NHS in England 2007-2013: A Cross-Sectional Study

Jon M Dickson<sup>\*1</sup>, Richard Jacques<sup>2</sup>, Markus Reuber<sup>3</sup>, Julian Hick<sup>4</sup>, Mike J Campbell<sup>2</sup>, Rebeka Morley<sup>5</sup>, Richard A Grünewald<sup>6</sup>

\* Corresponding author: Jon M Dickson, The Academic Unit of Primary Medical Care, The Medical School, The University of Sheffield, Room 215, 2nd Floor, Samuel Fox House, Northern General Hospital, Herries Road, Sheffield, S5 7AU. j.m.dickson@sheffield.ac.uk, 0114 222 2081 (tel), 0114 222 2219 (fax).

Keywords: neurology, epilepsy, health services, quality improvement

Word count: 3,549

1. The University of Sheffield - The Academic Unit of Primary Medical Care  
Samuel Fox House Northern General Hospital Herries Road, Sheffield S5 7AU  
United Kingdom of Great Britain and Northern Ireland

2. University of Sheffield - ScHARR  
Regent Court 30 Regent Street , Sheffield S1 4DA  
United Kingdom of Great Britain and Northern Ireland

3. The University of Sheffield  
Sheffield  
United Kingdom of Great Britain and Northern Ireland

4. Baslow Health Centre  
Baslow, Derbyshire  
United Kingdom of Great Britain and Northern Ireland

5. Health IQ  
London

United Kingdom of Great Britain and Northern Ireland

6. Sheffield Teaching Hospitals NHS Foundation - Department of Neurosciences

Sheffield

United Kingdom of Great Britain and Northern Ireland

For peer review only

**Aims**

To quantify the frequency, characteristics, geographical variation and costs of emergency hospital care for suspected seizures.

**Design**

Cross-sectional study using routinely collected data (Hospital Episode Statistics).

**Setting**

The National Health Service (NHS) in England 2007-2013.

**Participants**

Adults who attended an emergency department (ED) or were admitted to hospital.

**Results**

In England (population 2011: 53.11 million, 41.77 million adults), suspected seizures gave rise to 50,111 unscheduled admissions per year amongst adults ( $\geq 18$  years). This is 47.1% of unscheduled admissions for neurological conditions and 0.71% of all unscheduled admissions. Only a small proportion of admissions for suspected seizures were coded as status epilepticus (3.5%) and there were a very small number of dissociative (non-epileptic) seizures. The median length of stay for each admission was 1 day, the median cost for each admission was £1,651 (\$2,175) and the total cost of all admissions for suspected seizures in England was £88.2 million (\$116.2 million) per year. 16.8% of patients had more than one admission per year. There was significant geographical variability in the rate of admissions corrected for population age and gender differences and some areas had rates of admission which were consistently higher than the average.

**Conclusions**

Our data show that suspected seizures are the most common neurological cause of admissions to hospital in England, that re-admissions are common and that there is significant geographical variability in admission rates. This variability has not previously been reported in the published literature. The cause of the geographical variation is unknown; important factors are likely to include prevalence, deprivation and clinical practice and these require further investigation. Dissociative seizures are not adequately diagnosed during ED attendances and hospital admissions.

### Strengths and limitations of this study

This study is based on hospital episode statistics (HES) data which includes all attendances at emergency departments (over 93 million) and all in-patient admissions to hospital (over 42 million) in England during a six-year period (2007-2013).

This is the first published study of unscheduled admissions for suspected seizures using HES data.

HES data uses ICD-10 for diagnostic coding facilitating comparisons with other national and international studies where ICD-10 is used.

We have assumed that HES diagnosis codes are accurate compared to gold standard clinical diagnoses for epilepsy and seizures but further research is required to confirm this.

**Introduction**

Epilepsy is the most common chronic disabling neurological disease worldwide [1], it is an ambulatory care sensitive condition (ACSC) [2] and sub-optimal ambulatory (routine or scheduled) care can lead to unnecessary emergency care, which is often associated with morbidity and impaired quality of life [3]. Estimates vary internationally [4] [5] [6] [7] [8] [9] but most studies suggest that approximately 70% of people with epilepsy will become free of seizures with optimal treatment. The overall seizure freedom rate achieved in the United Kingdom (UK) is around 50% [10] [11] [12, 13]. This implies that approximately one-in-five patients with epilepsy may be having seizures that could be prevented [5]. In the UK, some epilepsy services are world-leading but the quality of care is geographically variable, and patients in many areas do not have access to optimal monitoring and treatment [14]. Many patients who have active epilepsy are not under the care of an epilepsy specialist [4] [15]. Epileptic seizures may give rise to potentially avoidable unplanned attendances at hospital emergency departments (EDs) (formerly known as accident and emergency departments, A&E) or admission to hospital, and management decisions may be complex, require expertise, training and guidance. However, after a seizure, patients are often seen by paramedics, junior doctors and physicians without particular expertise in epilepsy.

Precise estimates vary, but in England (population in 2011: 52.96 million, 42.96 million adults [16]), seizures give rise to 60,000 seizure-related ED attendances (2-3% of all attendances) (113 per 100,000 of the general population per year) [17], and 40,000 hospital admissions (76-148 per 100,000/year) which is 9.5% of all admissions for ACSCs [17] [18]. There were over one million emergency admissions for chronic ACSCs in England in the financial year 2011/12 and over 600,000 for acute conditions that should not normally require hospital admission [19]. Admissions in both categories have been rising, and suspected seizures are one of the largest contributors to these admissions. We should point out that, although most suspected seizures are epileptic [15], this is a diagnostically heterogeneous group and other conditions can mimic epilepsy [20]. We use the term ‘suspected seizure’ to encompass how this group of patients usually present to medical practitioners i.e. transient loss of consciousness and convulsions leading observers (usually not medical professionals) to suspect an epileptic seizure and to report this to emergency services.

The National Health Service (NHS) in the UK is tax-funded and free at the point of delivery. It is the provider of almost all health care in the UK, especially emergency care. The emergency care structure in the UK, with universal access to healthcare, and non-overlapping emergency services offers opportunities to study emergency presentations with suspected seizures which do not exist in many other countries. Most NHS services are commissioned locally by geographically based clinical commissioning groups (CCGs) which came into being on 01/04/13 (they were preceded by primary care trusts (PCTs) which had similar geographical boundaries) [21]. HES (Hospital Episode Statistics) is a data warehouse containing routinely collected data from all admissions, outpatient appointments and ED attendances at NHS hospitals in England. The data are collected during a patients’ hospital attendance for the purpose of allowing hospitals to be paid for the care that they deliver but it is also a powerful tool for research. Our aims were to quantify the frequency, the characteristics and the costs of emergency department attendances and unplanned hospital admissions care for suspected seizures, and to identify geographical variation that may reflect disparities in ambulatory care or emergency care pathways such as ED admission guidelines.

**Methods**

*Data Source and Case Ascertainment*

HES data was accessed by a third-party organisation (Health IQ) that searched the HES A&E database for attendances and the HES in-patient database for unscheduled/emergency in-patient admissions in adults (≥ 18 years) in the NHS in England during the period 1 April 2007 and 31 March 2013 (six

financial years). Six years of data was judged sufficient to explore re-admission rates after the index admission and the cut-off of 31/03/13 was chosen to avoid any potential disruption from 01/04/13 as CCGs came into being.

#### *Emergency Department (ED) Data*

We used the HES A&E Data Dictionary [22] central nervous system (CNS) codes (two character and three character): CNS excluding stroke (24), CNS epilepsy (241) and CNS other non-epilepsy (242). We used code 241 as a proxy for our target population of patients with suspected seizures. Although Emergency Department (ED) is now the preferred term in most countries this section of the HES data retains its historic title of HES A&E (accident and emergency) data.

#### *In-Patient Data*

We searched the in-patient database for admissions (spells) where  $\geq 1$  episode (a period under the care of an individual consultant) during the admission/spell had a primary diagnosis code for a disease of the nervous system. Three separate searches were undertaken: 1) admissions where the primary diagnosis was suspected seizure, 2) admissions where the primary diagnosis was a neurological condition other than a suspected seizure (the full list of ICD-10 codes used to generate diagnostic categories are listed in the appendices (see supplementary file), we used ICD-10 chapter six plus two codes from other chapters), 3) admissions where the primary diagnosis was dissociative seizures. The following codes were used in the search for suspected seizures: G40 (epilepsy), G41 (status epilepticus) and R56.8 (other and unspecified convulsions). The following codes which are closely related to suspected seizures were not included: R56.0 (Febrile convulsions), P90 (Convulsions of new born), O15 (eclampsia) and R56.1 (post traumatic seizures). Stroke/TIA (G45/G56) was not included in any of the searches because these conditions are classified in ICD-10 as cerebrovascular diseases. F44.5 was used for dissociative convulsions/seizures. We also calculated the number of times patients were readmitted with the same codes over the study period. We calculated the time from first admission to either first readmission or to the end of the study period and plotted this using a Kaplan-Meier curve. We included data on costs for ED attendances and in-patient admissions. The cost of each A&E attendance was based on: (Health Resources Group (HRG) attributed to each attendance) + (Investigation and Treatment cost) x Market Forces Factor (MFF). The cost of each admission was based on: (HRG attributed to each admission + trim-point (base) cost + Added Bed days cost) x Market Forces Factor (MFF).

#### *Geographical Variation in Seizure/Convulsions Admissions*

We calculated an age and sex directly standardised rate for the number of emergency admissions for each PCT (151 PCTs in total). The numerator of the rate is calculated from Hospital Episode Statistics (HES) inpatient data and the denominator is the 2011 PCT population estimate from the Office for National Statistics (ONS) [1]. Adjustments were made for changes to the PCTs in terms of their names and codes and the merger of several trusts. The direct standardisation adjusted for age and sex with age categorised into three groups: 18-34, 35-64 and 65 and over. The age-sex specific standard population used in the analysis was calculated by grouping the populations of all PCTs from the ONS dataset [23].

To look at the distribution of directly standardised rates and to identify possibly outlying PCTs (low or high admission rates), funnel plots were drawn for each year [24]. The plots show the observed age and sex directly standardised rate for each PCT against the primary care trust population. In order to identify outliers, an over-dispersion model was used to draw control limits around the target outcome – that is, the weighted mean of the directly standardised rates [25]. This method allows an over-dispersion factor to be calculated that inflates the null variance and allows for any unexplained variation between the PCTs. If all PCTs were included in the estimate of the over-dispersion factor, then PCTs that are truly outlying would inflate the parameter unduly and may not

appear as outliers. Therefore when estimating the over-dispersion parameter a trimming approach was adopted to exclude the top and bottom 10% of PCTs (20% x 151 = 31) based on their z-score (a scaled difference between the observed rate and the target rate). If no true outliers existed then the estimate of the over-dispersion parameter would only be minimally affected by this procedure.

*Patient and Public Involvement*

Patients and the public were not involved in this research.

**Results**

*Emergency Department HES Data*

During the study period (2007-13), 93,806,757 attendances were recorded at ED departments in England, a mean of 15,634,460 attendances per year. There were 146,729 epilepsy (code 241) attendances at ED (mean: 24,455 per year), representing 0.16% of all ED attendances and 0.33% of ED attendances that were given an HES A&E diagnosis code. The average cost of an ED attendance for suspected seizures (code 241) during the study period was £123 (\$172). The total costs related to ED attendances for suspected seizures was £18,047,667 (\$25,174,595) (£123 x 146,729), an average of £3,007,945 (\$4,195,766) per year.

*In-Patient HES Data*

There were a total of 42,201,775 emergency admissions in the NHS in England between 1 April 2007 and 31 March 2013 (six financial years) of which 638,150 (1.5%) were for neurological conditions (after exclusions). 300,668 (47.1%) neurological admissions were for suspected seizures making this by far the most common neurological cause for unscheduled admissions (0.71% of unscheduled admissions for all causes). Figure 1 shows the number of unscheduled neurological admissions by diagnosis. There were 1,074 emergency admissions coded as dissociative convulsions (F44.5) during the study period (mean 179/annum).

Suspected seizures accounted for a mean of 50,111 admissions per year, representing 0.71% (range 0.67-0.74%) of unscheduled admissions for all causes during the study period. 54.3% of the admissions for epilepsy/seizure/convulsion were coded as G40 (epilepsy), 42.2% were coded R56.8 (other and unspecified convulsions) and 3.5% were coded G41 (status epilepticus). 93.4% of admissions were via A&E and 3.6% were via GPs. More men (54.6%) than women (45.4%) had unplanned hospital admissions with these diagnostic codes. The median length of stay was 1 day (IQR=0-3, range 0-988). The median cost per admission was £1,651 (\$2,1750) (IQR £1091-1858, range £0-£217,998) and the mean total cost per year was £88,217,138 (\$116,224,315) (during the study period).

*Re-admissions*

Over the six-year study period, 83.2% of patients had one admission per year and 16.8% had more than one admission per year (12.1% had two admissions per year, 3.4% had 3 admissions per year and 1.3% had more than 3 admissions per year). Figure 2 shows Kaplan-Meier survival curves for time to first readmission. The curve indicates that overall there was a probability of 0.20 of readmission during the first year of the study and a 0.34 probability of readmission during the 6-year study period. The probability of re-admission (first year, full 6-years) for each ICD10 code (coding of first admission) was G40 (0.22 / 0.38), G41 (0.13 / 0.23) and R56.8 (0.11 / 0.18).

*Geographical Variability in Admissions*

The weighted mean number of admissions for suspected seizures per 100,000 over the study period was 121.0. Figure 3a shows a funnel plot of standardised admission rates for suspected seizures (G40 + G41 + R56.8) for each PCT (Figure 3b and 3c show rates for individual ICD-10 codes). Figure



3a demonstrates that four PCTs (2.6%) were identified as being outliers more than 3SDs above the mean, when less than one would have been expected if PCTs were all behaving the same, and no PCT was found to be more than 3SDs below the mean. Data on individual PCTs is available in the appendices (see supplementary file).

### Ethics

HES data was provided by Health IQ (a real world data company that has access to HES data), in an aggregated, non-identifiable and suppressed format in line with NHS Digital guidelines. The work was approved by the University of Sheffield research ethics committee (project number 001932).

## **Discussion**

### **In-Patient Admissions for Suspected Seizures**

Our data show that suspected seizures are the most common neurological cause of admission to hospital in England. We have deliberately used the term suspected seizure rather than epilepsy because of the uncertainty around the diagnosis of seizures and epilepsy [20]. The cause of many seizures and other paroxysmal events involving collapse, and loss of consciousness, remain uncertain even after hospital admission and review by a specialist. This is further complicated by the difficulty distinguishing epileptic from psychogenic non-epileptic seizures [26] [27], inconsistencies between ILAE classifications and ICD-10 categories, and the transposition of doctors notes by hospital coders into ICD-10 codes. We used ICD-10 codes, G40, G41 and R56.8 to identify patients with suspected seizures. The same (or almost the same) ICD-10 codes have been used in other large studies of variation in admissions and quality of care for suspected seizures [28] [29] [17]. There is evidence that HES diagnostic coding is accurate overall, but there is significant variability amongst the published studies [30]. Research from Canada shows that the diagnosis of epilepsy (G40 and G41) by hospital coders is specific but that the use of R56.8 is required to improve sensitivity – at the cost of reducing overall specificity [31]. There have been no similar studies in the UK looking specifically at seizures/epilepsy i.e. comparing HES ICD-10 diagnosis codes with a gold standard diagnosis.

The only previously published study using HES data [28] which is directly comparable to this study showed that seizures gave rise to 1.36% (interhospital range 1.2-1.6%) of all emergency admissions [28] which is approximately twice the rate that we found (0.71%; range 0.67-0.74%). Grainger et al included patients using primary and secondary diagnoses whereas our study exclusively used the primary diagnosis. Grainger et al also used the diagnosis code for the last episode in the spell i.e. the discharge diagnosis. These two methodological differences probably account for the discrepancy in the results between their study and ours. There have been no published studies modelling the effects of different methods of case ascertainment on admissions rates in terms of primary and secondary diagnoses but there is likely to be a trade-off between sensitivity and specificity using the different methods. We propose that, based on the current evidence, G40+G41+R56.8 is the best combination of codes to identify patients with suspected seizures. But we conclude that further research is required on the optimal method of identifying admissions for suspected seizures in terms of ICD-10 codes, primary +/- secondary diagnoses and episodes/spells.

### *Re-Admissions*

After an admission to hospital for a suspected seizure (or an attendance at ED) the aim of management should be to make an accurate diagnosis, manage urgent/emergency problems, optimise ongoing medical treatment (including referral to specialist outpatient services) and provide advice on self-care to reduce the risk of re-admission after discharge. Active epilepsy should trigger review by an epilepsy specialist to prevent further seizures and/or to refine the patients emergency care plan but this opportunity is often missed [15] [17] [32] [33] [20] and patients therefore remain at risk of further seizures and the associated morbidity [34], mortality [35] and health services costs

[36] [37] of poorly controlled epilepsy. Our data show that 22.4% of patients had more than one admission per year and that overall there was a 34% chance of readmission after a suspected seizure within 6 years which provides further evidence of potentially avoidable admissions and poor quality care. However, quantification of avoidable admissions using HES data is complicated by the diagnostic uncertainty and the difficulty distinguishing between those cases that are truly ambulatory care sensitive (e.g. sub-optimally treated patients with active epilepsy) and those which are not (e.g. intractable epilepsy, first epileptic seizures which don't meet the criteria for epilepsy [38], and many more). Some national performance indicators are predicated on the notion that good quality scheduled care can prevent all admissions for seizures [29] [39, 40] which makes their validity doubtful.

*Geographical Variability and Service Provision*

There is significant geographical variability in the directly standardised admission rates and there are four geographical areas (PCTs) whose mean rate throughout the study period is greater than 3SDs from the mean. This variability has not previously been reported in the published literature. Our research was not designed to investigate potential causes of the variability and the expected or optimal rate of hospital admissions per 100,000 is unknown. Factors which are likely to influence admission rates for suspected seizures are the prevalence of epilepsy, deprivation, the quality of ambulatory care and local practice in the emergency care system such as care pathways (including the accessibility of neurological advice) and ED discharge protocols. The four outliers ( $\geq 3$  SDs above the mean) are post-industrial areas in the north of England which is consistent with the hypothesis that deprivation is an important factor. Further research is required to investigate the causes of the variability demonstrated in this study. Comparison of rates of admissions for suspected seizures should be compared with all-cause admissions in future studies.

The study period for our data-set ends on 31/03/13 and is based on PCTs. CCGs came into being on 01/04/13 and although the geographical boundaries of many PCTs were identical to the CCGs that replaced them, some were different, and furthermore the initial configuration of CCGs has subsequently been changed. As such our PCT-based data is not directly comparable with current CCGs but this does not detract from the conclusion that there is significant geographical variability and commissioners may wish to review the up-to-date data.

*Under-diagnosis of Dissociative Seizures*

The EPIC 2 [15] study showed that 7.4% of all in-patient admissions in a UK centre which resulted from a 999 call for a suspected seizure were caused by dissociative seizures (DS) (ICD-10 code F44.5, also known as psychogenic nonepileptic seizures, PNES, or manifestations of non-epileptic attack disorder, NEAD) [15]. Based on this data we would estimate 22,250 ( $7.4\% \times 300,668$ ) (3,709 per year) admissions during the study period for DS but in our study the ICD-10 code for DS identified only 1,074 admissions in total (179/annum). Despite the fact that the nosology of DS is controversial and a number of different terms are used in the medical literature there is only one ICD-10 code for DS/PNES/NEAD, so it seems that miscoding is unlikely to be the cause of this discrepancy. The unexpectedly low number of cases coded as being admitted with DS adds to the evidence of under-diagnosis of DS by doctors in acute medical settings and of the misdiagnosis of DS as epileptic seizures [41] [42] [43] [44] [45]. In addition to case reports and case series of patients with DS receiving inappropriate emergency treatment for status epilepticus other indirect evidence for this problem comes from primary care studies demonstrating that non-expert diagnoses of epilepsy are regularly inaccurate and studies based in secondary care demonstrating that the mean diagnostic delay of DS is several years, with most patients with DS initially receiving treatment for epilepsy [46] [47] [48]. It may be that many patients who were admitted during the study period with a DS were actually coded using G40, G41 or R56.8. More research is required to accurately quantify the number of unplanned hospital admissions with DS, but as the management of dissociative seizures is

very different from that of epileptic seizures, this observation provokes concern that the ED management of psychogenic seizures may be suboptimal.

#### *A&E Data*

The HES A&E data dictionary uses a crude system of 58 diagnosis codes (at three-character level). Coding is done by individual clinicians many of who are junior doctors who have not had any training for this role. Using the HES A&E diagnosis code 241 (CNS epilepsy) for case ascertainment shows an average of 24,455 attendances per year that is significantly less than the number of admissions for suspected seizures based on the in-patient data. Many A&E attendances were classified as “unknown” or “diagnosis not classifiable” and it is not clear how the other two HES A&E neurology codes relate to the diagnosis of epilepsy. We conclude that HES A&E data is not of sufficient quality to make robust estimates of the number of attendances related to suspected seizures. The Emergency Care Data Set (ECDS) will supersede the current ED data and diagnosis codes will be based on the SNOMED-CT diagnostic codes [49] which may improve the quality of the data [50]. Until the issues with data quality in ED are resolved this will remain an important data-gap which undermines attempts to undertake high quality research, plan services and to evaluate service innovations.

#### *Implications for Clinical Care and Public Health in the United Kingdom and Internationally*

Epileptic seizures are usually self-limiting and in themselves are not medical emergencies but they account for a large number of emergency admissions many of which are potentially preventable. Important and potentially modifiable factors which give rise to unnecessary admissions are the quality of ambulatory care, advanced care planning and the configuration of emergency care pathways. Approximately 1 in 5 patients with epilepsy are having regular seizures which could be prevented with optimal treatment. Improvements in seizure freedom rates would in turn be likely to reduce the number of unscheduled admissions. Care planning for patients with intractable epilepsy in the form of an emergency care plan shared with relatives, friends and carers may reduce demand on emergency services. Emergency care pathways, designed to identify patients that can be safely managed without emergency attendance/admission to hospital, and to divert them to urgent but scheduled appointments in specialised services may improve care and reduce unnecessary admissions. Our research is based on data from the NHS in England and is inevitably context-specific, but research from other European countries shows similar problems with quality of ambulatory care for epilepsy, variability in services and high costs from potentially avoidable admissions [51] [52]. Prevalence of epilepsy and the incidence of seizures has much wider determinants than health-care provision. Alcohol, deprivation and comorbidities linked with seizures such as cerebrovascular disease, are all relevant and require a public-health approach to tackle them.

#### *Data Sharing Statement*

No unpublished data from this study is available.

#### *Contributorship Statement*

The idea for the study came from RAG. JMD was the Chief Investigator and he worked with the other authors (RJ, MR, JH, MJC, RM, RAG) to develop the protocol. JMD, JH and RJ took the lead with data analysis. JMD took the lead with writing the manuscript and the other authors (RJ, MR, JH, MJC, RM, RAG) contributed to the manuscript and approved the final version.

#### *Competing Interests and Acknowledgement*

Yes, there are competing interests for one or more authors. This work was supported by UCB Pharma Ltd. through an educational grant the University of Sheffield (JMD, RAG, MR, JH) (grant X/008805-1) and consultancy fees to Health IQ (RM). UCB had no editorial control on the contents.

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

For peer review only

Figure 1: Neurological diagnoses ranked by number of emergency hospital admissions between 31/04/07 and 31/03/13. Suspected seizures = G40 + G41 + R56.8.

Figure 2: Kaplan-Meier plots showing the time to first readmission after a suspected seizure when the first admission was for G40 + G41 + R56.8, G40, G41, R56.8. ICD-10 codes: G40 (epilepsy), G41 (status epilepticus) and R56.8 (other and unspecified convulsions).

Figure 3: Funnel plots showing the directly standardised emergency admission rate per 100,000 of the adult population 2007-2013 in each PCT. (A) G40 + G41 + R56.8, (B) G40, (C) R56.8. Each dot represents a PCT, the solid line shows the weighted mean for the standardised admission rate, and the dashed and dotted line shows 2 and 3 standard deviations from the mean respectively. ICD-10 codes: G40 (epilepsy), G41 (status epilepticus) and R56.8 (other and unspecified convulsions). There was not enough data to age-sex standardise the G41 diagnosis code.

References

1. Banerjee, P.N., D. Filippi, and W. Allen Hauser, *The descriptive epidemiology of epilepsy-a review*. *Epilepsy Res*, 2009. **85**(1): p. 31-45.
2. Bardsley, M., et al., *Is secondary preventive care improving? Observational study of 10-year trends in emergency admissions for conditions amenable to ambulatory care*. *BMJ Open*, 2013. **3**: p. e002007.
3. Gupta, S., et al., *Understanding the burden of idiopathic generalized epilepsy in the United States, Europe, and Brazil: An analysis from the National Health and Wellness Survey*. *Epilepsy Behav*, 2016. **55**: p. 146-56.
4. Thurman, D.J., et al., *Health-care access among adults with epilepsy: The U.S. National Health Interview Survey, 2010 and 2013*. *Epilepsy Behav*, 2015.
5. Moran, N.F., et al., *Epilepsy in the United Kingdom: seizure frequency and severity, anti-epileptic drug utilization and impact on life in 1652 people with epilepsy*. *Seizure*, 2004. **13**(6): p. 425-33.
6. *Relationship Between Seizure Frequency and Costs and Quality of Life of Outpatients with Partial Epilepsy in France, Germany and the United Kingdom*.
7. *ILAE Commission on the Burden of Epilepsy, Subcommittee on the Economic Burden of Epilepsy: Final report 1998-2001*.
8. Sander, J.W., *The Use of Antiepileptic Drugs - Principles and Practice*. *Epilepsia*, 2004. **45**(Suppl. 6): p. 28-34.
9. Kwan, P. and M.J. Brodie, *Early identification of refractory epilepsy*. *The New England Journal of Medicine*, 2000. **342**(5): p. 319.
10. Association of British Neurologists, *Acute Neurology services survey 2014*. 2014.
11. Jon M Dickson, Peter A Scott, and Markus Reuber, *Epilepsy Service Provision in the National Health Service in England in 2012*. *Seizure*, 2015. **30**: p. 26-31.
12. Pearson, M., et al., *National Audit of Seizure Management in Hospitals (Clinical Report)*. 2012.
13. Pearson, M., et al., *National Audit of Seizure Management in Hospitals (Clinical Report)*. 2014.
14. Dickson, J.M., P.A. Scott, and M. Reuber, *Epilepsy service provision in the National Health Service in England in 2012*. *Seizure*, 2015. **30**: p. 26-31.
15. Dickson, J., et al., *Cross-sectional study of the hospital management of adult patients with a suspected seizure (EPIC2)*. *BMJ Open*, 2017. **7**: p. e015696.
16. Office for National Statistics. *Time series: England population mid-year estimate*. 15/02/18]; Available from: [www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/timeseries/enpop/pop](http://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/timeseries/enpop/pop).
17. Dixon, P., et al., *National Audit of Seizure management in Hospitals (NASH): results of the national audit of epilepsy in the UK*. *BMJ Open*, 2015. **5**: p. e007325.
18. Tian, Y., A. Dixon, and H. Gao, *Emergency hospital admissions for ambulatory care-sensitive conditions: identifying the potential for reductions*, in *Data Briefing*. 2012, The King's Fund.
19. The NHS Information Centre, *CCG outcomes indicator set - emergency admissions*. 2013.
20. Malmgren, K., M. Reuber, and R. Appleton, *Differential diagnosis of epilepsy*, in *Oxford Textbook of Epilepsy and Epileptic Seizures 2013*, Oxford University Press.
21. Fund., T.K. *The new NHS: clinical commissioning groups*. 04/01/18]; Available from: <https://www.kingsfund.org.uk/projects/new-nhs/clinical-commissioning-groups>.
22. Health and Social Care Information Centre. *HES A&E Data Dictionary*. January 2016]; Available from: <http://www.hscic.gov.uk/article/3966/HES-AE-Data-Dictionary>.
23. Office for National Statistics. *Primary Care Organisations Mid-Year Population Estimates, Mid 2011 (Census Based)*. Available from: <http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcn%3A77-297507>.



24. Spiegelhalter, D., *Funnel plots for comparing institutional performance*. . Stat Med, 2005. **24**: p. 1185-202.
25. Spiegelhalter, D.J., *Handling over-dispersion of performance indicators*. Qual Saf Health Care, 2005. **14**(5): p. 347-51.
26. Wasserman, D. and M. Herskovitz, *Epileptic vs psychogenic nonepileptic seizures: a video-based survey*. Epilepsy and Behaviour, 2017. **73**: p. 42-45.
27. Jackson, A., L. Teo, and U. Seneviratne, *Challenges in the first seizure clinic for adult patients with epilepsy*. Epileptic Disorders, 2016. **18**: p. 305-314.
28. Grainger, R., et al., *Referral patterns after a seizure admission in an English region: an opportunity for effective intervention? An observational study of routine hospital data*. BMJ Open, 2016. **6**(1): p. e010100.
29. NHS England, *The NHS Atlas of Variation in Healthcare*. 2015.
30. Burns, E.M., et al., *Systematic review of discharge coding accuracy*. J Public Health (Oxf), 2012. **34**(1): p. 138-48.
31. Jette, N., et al., *How accurate is ICD coding for epilepsy?* Epilepsia, 2010. **51**(1): p. 62-9.
32. National Institute of Clinical Excellence, *The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care*. 2012.
33. National Institute for Health and Care Excellence, *Transient loss of consciousness ('blackouts') management in adults and young people*. 2010.
34. Baker, G., A. Jacoboy, and B. D., *Quality of life of people with epilepsy: a European study*. Epilepsia, 1997. **38**: p. 353-362.
35. Lhatoo, S., et al., *Mortality in Epilepsy in the First 11 to 14 Years after Diagnosis: Multivariate Analysis of a Long-Term, Prospective, Population-Based Cohort*. Annals of Neurology, 2001. **2001**: p. 336-344.
36. Manjunath, R., et al., *Burden of uncontrolled epilepsy in patients requiring an emergency room visit or hospitalization*. Neurology, 2012. **79**: p. 1908-1916.
37. Galarraga, J., R. Mutter, and J. Pines, *Costs associated with ambulatory care sensitive conditions across hospital-based settings*. Academic Emergency Medicine, 2015. **22**: p. 172-181.
38. Fisher, R.S., et al., *ILAE official report: a practical clinical definition of epilepsy*. Epilepsia, 2014. **55**(4): p. 475-82.
39. NHS England, *CCG Outcomes Indicator Set 2014/15: technical guidance*. December 2013.
40. Department of Health, *The NHS Outcomes Framework 2015/16*. 2014.
41. Reuber, M., et al., *Clinical significance of recurrent psychogenic nonepileptic seizure status*. Journal of Neurology, 2003. **250**(11): p. 1355-1362.
42. Reuber, M., et al., *Failure to recognize psychogenic nonepileptic seizures may cause death*. Neurology, 2004. **62**(5): p. 834-835.
43. Gunatilake, S., H. De Silva, and G. Ranasinghe, *Twenty-seven venous cutdowns to treat pseudostatus epilepticus*. 1997. **6**(1): p. 71-72.
44. Howell, S., L. Owen, and D. Chadwick, *Pseudostatus epilepticus*. Quarterly Journal of Medicine, 1989. **71**(266): p. 507-519.
45. Holtkamp, M., et al., *Diagnosis of psychogenic nonepileptic status epilepticus in the emergency setting*. Neurology, 2006. **66**(11): p. 1727-1729.
46. Leach, J.P., et al., *Epilepsy in the UK: misdiagnosis, mistreatment, and undertreatment? The Wrexham area epilepsy project*. Seizure, 2005. **14**(7): p. 514-20.
47. Reuber, M., et al., *Diagnostic delay in psychogenic nonepileptic seizures*. Neurology, 2002. **2002**(58): p. 493-495.
48. Kerr, W., et al., *Diagnostic delay in psychogenic seizures and the association with anti-seizure medication trials*. . Seizure, 2016. **40**: p. 123-126.
49. SNOMED International. *SNOMED CT*. [Accessed 04/01/18]; Available from: <https://www.snomed.org/snomed-ct>.



50. Dickson, J., S. Mason, and A. Bailey, *Emergency department diagnostic codes: useful data?* Emergency Medicine Journal, 2017. **34**: p. 627.

51. Strzelczyk, A., et al., *Evaluation of health-care utilization among adult patients with epilepsy in Germany.* Epilepsy Behav, 2012. **23**(4): p. 451-7.

52. Begley, C.E. and E. Beghi, *The economic cost of epilepsy: a review of the literature.* Epilepsia, 2002. **43**(Suppl 4): p. 3-9.

For peer review only

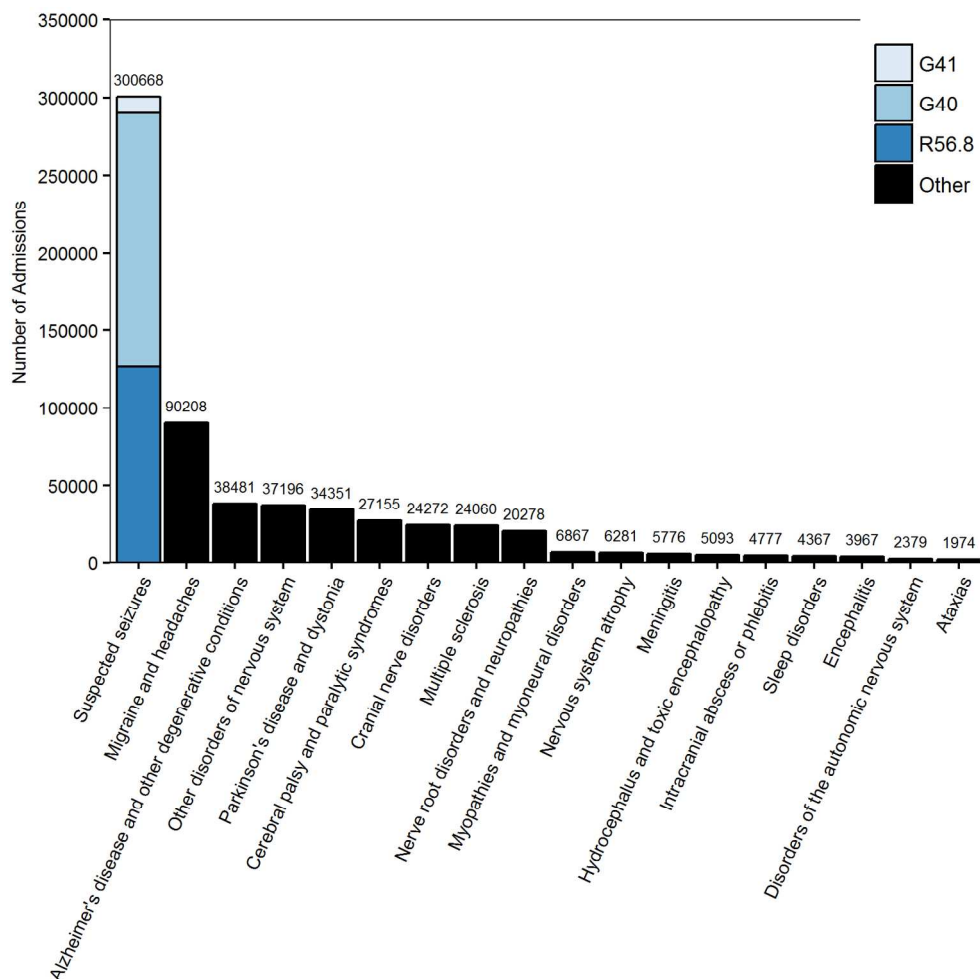


Figure 1: Neurological diagnoses ranked by number of emergency hospital admissions between 31/04/07 and 31/03/13. Suspected seizures = G40 + G41 + R56.8.

152x152mm (300 x 300 DPI)

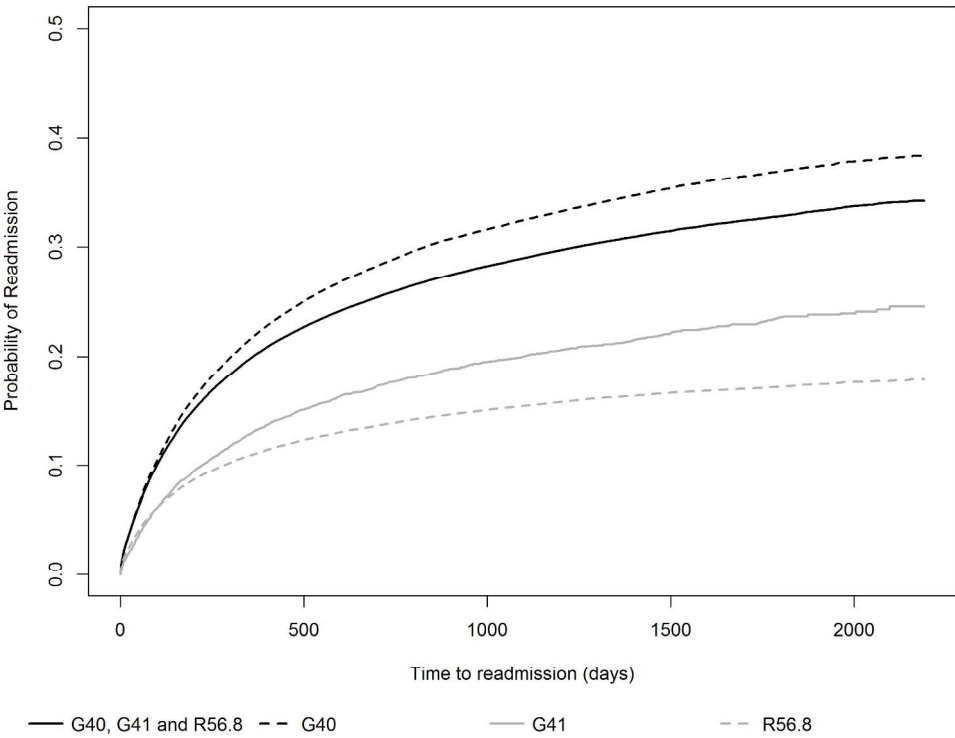


Figure 2: Kaplan-Meier plots showing the time to first readmission after a suspected seizure when the first admission was for G40 + G41 + R56.8, G40, G41, R56.8. ICD-10 codes: G40 (epilepsy), G41 (status epilepticus) and R56.8 (other and unspecified convulsions).

228x177mm (300 x 300 DPI)

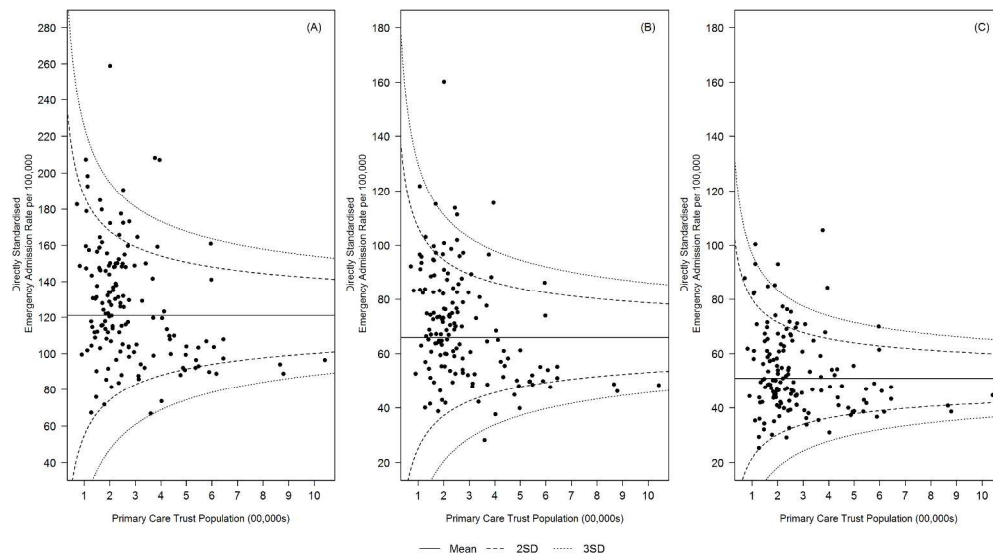


Figure 3: Funnel plots showing the directly standardised emergency admission rate per 100,000 of the adult population 2007-2013 in each PCT. (A) G40 + G41 + R56.8, (B) G40, (C) R56.8. Each dot represents a PCT, the solid line shows the weighted mean for the standardised admission rate, and the dashed and dotted line shows 2 and 3 standard deviations from the mean respectively. ICD-10 codes: G40 (epilepsy), G41 (status epilepticus) and R56.8 (other and unspecified convulsions). There was not enough data to age-sex standardise the G41 diagnosis code.

304x177mm (300 x 300 DPI)

Diagnosis Group Label	ICD-10	ICD10 Description
Migraine and headaches	G43	Migraine
	G44	Other headache syndromes
Alzheimer's disease and....	G30	Alzheimer's disease
	G31	Other degenerative diseases of nervous system, not elsewhere classified
	G32	Other degenerative disorders of nervous system in diseases classified elsewhere
Other disorders of nervous system	G93	Other disorders of brain
	G94	Other disorders of brain in diseases classified elsewhere
	G95	Other diseases of spinal cord
	G96	Other disorders of central nervous system
	G97	Post-procedural disorders of nervous system, not elsewhere classified
	G98	Other disorders of nervous system, not elsewhere classified
	G99	Other disorders of nervous system in diseases classified elsewhere
Parkinson's disease and dystonia	G20	Parkinson's disease
	G21	Secondary parkinsonism
	G23	Other degenerative diseases of basal ganglia
	G24	Dystonia
	G25	Other extrapyramidal and movement disorders
Cerebral palsy and paralytic syndromes	G80	Cerebral palsy
	G81	Hemiplegia
	G82	Paraplegia and tetraplegia
	G83	Other paralytic syndromes
Cranial Nerve Disorders	G50	Disorders of trigeminal nerve
	G51	Facial nerve disorders
	G52	Disorders of other cranial nerves
	G53	Cranial nerve disorders in diseases classified elsewhere
Multiple sclerosis	G35	Multiple sclerosis
	G36	Other acute disseminated demyelination
	G37	Other demyelinating diseases of central nervous system
Nerve Root Disorders and neuropathies	G54	Nerve root and plexus disorders
	G55	Nerve root and plexus compressions in diseases classified elsewhere
	G56	Mono-neuropathies of upper limb

	G57	Mono-neuropathies of lower limb
	G58	Other mono-neuropathies
	G59	Mono-neuropathy in diseases classified elsewhere
	G60	Hereditary and idiopathic neuropathy
	G61	Inflammatory polyneuropathy
	G62	Other polyneuropathies
	G63	Polyneuropathy in diseases classified elsewhere
	G64	Other disorders of peripheral nervous system
Myopathies and myoneural disorders	G70	Myasthenia gravis and other myo-neural disorders
	G71	Primary disorders of muscles
	G72	Other myopathies
	G73	Disorders of myo-neural junction and muscle in diseases classified elsewhere
Nervous system atrophy	G12	Spinal muscular atrophy and related syndromes
	G13	Systemic atrophies primarily affecting central nervous system in diseases classified elsewhere
	G14	Post-polio syndrome
Huntington's disease	G10	Huntington's disease
Meningitis	G00	Bacterial meningitis, not elsewhere classified
	G01	Meningitis in bacterial diseases classified elsewhere
	G02	Meningitis in other infectious and parasitic diseases classified elsewhere
	G03	Meningitis due to other and unspecified causes
Hydrocephalus and toxic encephalopathy	G91	Hydrocephalus
	G92	Toxic encephalopathy
Intra-cranial abscess or phlebitis	G06	Intracranial and intra-spinal abscess and granuloma
	G07	Intracranial and intra-spinal abscess and granuloma in diseases classified elsewhere
	G08	Intracranial and intra-spinal phlebitis and thrombophlebitis
Sleep disorders	G47	Sleep disorders
Encephalitis	G04	Encephalitis, myelitis and encephalomyelitis
	G05	Encephalitis, myelitis and encephalomyelitis in diseases classified elsewhere
Disorders of the autonomic nervous system	G90	Disorders of autonomic nervous system
Ataxias	G11	Hereditary ataxia

PCT CODE	PCT NAME	Rate Y1	Rate Y2	Rate Y3	Rate Y4	Rate Y5	Rate Y6	Rate All
5 E1	STOCKTON-ON-TEES TEACHING PCT	129.66	136.59	147.01	139.65	140.41	131.28	137.43
5A3	SOUTH GLOUCESTERSHIRE PCT	73.21	88.33	82.82	83.29	87.12	73.39	81.36
5A4	HAVERING PCT	100.52	94.37	120.09	122.63	122.21	89.93	108.29
5A5	KINGSTON	67.25	48.45	64.10	73.96	81.04	69.66	67.41
5A7	BROMLEY PCT	80.90	125.57	109.69	102.18	88.63	100.45	101.24
5A8	NHS GREENWICH	80.75	88.28	88.80	98.33	95.17	99.28	91.77
5A9	BARNET PRIMARY CARE TRUST	70.47	113.05	113.10	111.81	106.45	108.84	103.95
5AT	HILLINGDON PCT	111.80	101.00	124.18	115.34	105.00	126.16	113.91
5C1	ENFIELD PCT	64.45	84.92	95.53	86.72	71.88	99.15	83.78
5C2	BARKING AND DAGENHAM PCT	119.75	114.87	124.15	162.35	125.39	136.75	130.54
5C3	CITY AND HACKNEY TEACHING PCT	141.32	132.33	122.64	125.36	118.13	132.12	128.65
5C4	TOWER HAMLETS PRIMARY CARE TEAM	163.60	170.51	150.38	150.36	146.43	119.65	150.15
5C5	NEWHAM PRIMARY CARE TEAM	117.27	128.77	121.46	148.22	128.50	143.49	131.28
5C9	HARINGEY PCT	135.47	104.69	111.27	115.58	130.95	125.21	120.53
5CN	NHS HEREFORDSHIRE	82.31	94.12	89.42	103.61	94.64	77.41	90.25
5CQ	MILTON KEYNES PCT	101.74	121.76	103.71	123.29	122.16	98.31	111.83
5D7	NEWCASTLE PCT	145.13	128.02	136.25	137.09	141.20	139.71	137.90
5D8	NORTH TYNESIDE PCT	175.56	150.78	127.84	151.21	145.17	130.03	146.76
5D9	HARTLEPOOL PCT	148.91	138.08	207.39	175.41	203.56	222.55	182.65
5EF	NORTH LINCOLNSHIRE PCT	124.11	108.69	158.66	139.06	164.36	165.41	143.38
5EM	NOTTINGHAM CITY PCT	124.48	129.71	127.88	133.35	121.41	119.49	126.05
5ET	BASSETLAW	98.22	94.36	105.86	89.23	112.22	97.17	99.51
5F1	PLYMOUTH PRIMARY CARE TRUST	117.32	118.06	134.07	111.79	136.63	142.88	126.79
5F5	SALFORD PCT	152.29	131.29	161.18	148.40	140.36	142.22	145.96
5F7	STOCKPORT PCT	123.46	147.94	142.55	150.51	126.57	142.37	138.90
5FE	PORTSMOUTH CITY TEACHING PCT	153.70	144.34	143.41	155.46	155.43	125.47	146.30
5FL	BATH AND NORTH EAST SOMERSET PCT	122.26	122.07	96.23	95.94	106.49	109.84	108.80
5GC	LUTON PCT	98.89	104.94	97.83	103.08	129.70	138.30	112.12
5H1	HAMMERSMITH & FULHAM PCT	168.93	142.77	167.75	159.95	153.19	146.56	156.53
5H8	ROTHERHAM PCT	123.03	131.06	120.44	136.02	163.13	130.42	134.02
5HG	ASHTON LEIGH AND WIGAN PCT	135.72	149.07	149.97	155.71	156.39	152.21	149.85
5HP	BLACKPOOL PCT	172.44	169.54	192.81	186.40	229.81	204.59	192.60
5HQ	BOLTON PCT	142.81	135.52	123.90	135.49	118.28	154.04	135.01
5HX	EALING PCT	136.15	133.76	145.93	143.20	165.51	164.19	148.12
5HY	HOUNSLOW PCT	123.62	133.13	130.64	146.33	143.22	127.44	134.06
5J2	WARRINGTON PCT	133.10	132.08	162.74	137.10	171.79	149.00	147.64
5J4	KNOWSLEY	238.75	207.17	197.61	192.27	171.49	182.80	198.35
5J5	OLDHAM PRIMARY CARE TRUST	175.18	179.00	169.40	189.20	216.26	149.22	179.71
5J6	CALDERDALE PCT	158.79	158.67	159.96	164.06	156.03	154.62	158.69
5J9	DARLINGTON PCT	149.36	162.28	132.87	180.27	151.32	116.06	148.69
5JE	BARNLEY PCT	93.45	124.23	125.78	116.64	109.26	111.95	113.55
5JX	BURY PRIMARY CARE TRUST	127.82	135.91	106.84	158.44	135.17	117.77	130.33
5K3	SWINDON PCT	88.66	114.78	122.82	116.85	120.12	129.71	115.49
5K5	BRENT PCT	122.83	131.28	125.79	129.21	112.47	145.62	127.87
5K6	HARROW PCT	66.20	82.41	79.22	97.69	87.64	100.45	85.61
5K7	CAMDEN PRIMARY CARE TRUST	131.27	128.29	136.51	90.72	102.71	117.91	117.90
5K8	ISLINGTON PRIMARY CARE TRUST	142.64	170.43	195.60	157.63	158.22	145.52	161.67
5K9	CROYDON PRIMARY CARE TRUST	114.24	116.53	139.22	129.55	136.51	141.17	129.53
5KF	GATESHEAD PRIMARY CARE TRUST	145.27	171.59	168.88	148.79	168.36	149.88	158.80
5KG	SOUTH TYNESIDE PCT	139.59	151.25	151.19	191.47	161.01	150.18	157.45
5KL	SUNDERLAND TEACHING PRIMARY CARE TRUST	143.91	137.09	156.69	118.23	113.43	111.87	130.21
5KM	MIDDLESBROUGH PCT	195.28	223.36	204.92	198.60	219.14	202.55	207.31
5L1	SOUTHAMPTON CITY PCT	107.12	168.37	160.32	161.16	149.22	187.45	155.61
5L3	NHS MEDWAY	117.07	99.79	109.33	107.43	102.05	105.71	106.90
5LA	KENSINGTON AND CHELSEA PCT	99.10	116.45	112.81	114.74	134.81	110.07	114.66
5LC	WESTMINSTER PCT	126.99	123.35	120.79	120.78	130.65	109.34	121.98
5LD	LAMBETH PCT	180.64	139.72	175.87	194.79	171.32	202.89	177.54
5LE	SOUTHWARK PCT	142.34	140.35	134.14	182.78	148.38	153.72	150.28
5LF	LEWISHAM PCT	144.60	125.42	145.10	130.23	125.99	149.48	136.80
5LG	WANDSWORTH PCT	126.26	145.94	129.99	119.30	135.35	134.42	131.88
5LH	TAMESIDE AND GLOSSOP PRIMARY CARE TRUST	131.53	117.96	143.35	171.11	165.76	162.95	148.78
5LQ	BRIGHTON AND HOVE CITY TEACHING PCT	128.94	158.53	137.92	174.85	158.49	141.89	150.10
5M1	SOUTH BIRMINGHAM PCT	159.69	171.30	170.40	184.03	182.46	171.34	173.20
5M2	SHROPSHIRE COUNTY PRIMARY CARE TRUST	79.34	78.45	86.90	100.18	92.85	91.19	88.15
5M3	WALSALL TEACHING PCT	126.44	130.20	127.38	121.19	113.32	107.19	120.95
5M6	RICHMOND & TWICKENHAM	69.77	55.91	61.07	80.50	92.11	95.98	75.89
5M7	SUTTON & MERTON PCT	102.56	110.36	109.77	106.26	97.78	103.10	104.97
5M8	NORTH SOMERSET PCT	85.54	100.18	108.40	118.15	106.06	99.57	102.98
5MD	COVENTRY PRIMARY CARE TRUST	125.31	140.54	145.69	148.42	162.01	168.12	148.35
5MK	TELFORD & WREKIN PRIMARY CARE TRUST	90.02	94.56	122.95	92.18	114.20	112.43	104.39
5MV	WOLVERHAMPTON CITY PRIMARY CARE TRUST	121.54	103.81	134.50	117.15	132.10	123.70	122.13
5MX	HEART OF BIRMINGHAM TEACHING PCT	139.64	138.89	155.95	178.63	137.48	138.15	148.12
5N1	LEEDS PCT	140.76	170.49	162.08	162.65	173.56	156.50	161.01
5N2	KIRKLEES PCT	112.06	135.66	131.94	147.37	141.08	106.53	129.11

1	5N3	WAKEFIELD DISTRICT PCT	159.03	153.72	174.82	161.89	142.71	137.90	155.01
2	5N4	SHEFFIELD PCT	85.49	88.07	105.83	104.61	107.30	108.00	99.88
3	5N5	DONCASTER PCT	103.27	85.69	109.60	115.21	136.73	119.85	111.72
4	5N6	DERBYSHIRE COUNTY PCT	83.28	86.44	92.84	92.97	98.94	84.38	89.81
5	5N7	DERBY CITY PCT	105.14	124.38	115.30	127.32	136.29	122.53	121.83
6	5N8	NHS NOTTINGHAMSHIRE COUNTY	86.21	96.62	95.97	87.70	98.27	87.87	92.11
7	5N9	LINCOLNSHIRE PCT	90.33	98.68	103.91	109.39	117.55	121.13	106.83
8	5NA	REDBRIDGE PCT	110.12	119.98	125.64	122.08	103.53	109.86	115.20
9	5NC	WALTHAM FOREST PCT	111.79	125.26	154.38	161.43	153.85	156.64	143.89
10	5ND	COUNTY DURHAM PCT	106.95	117.06	122.06	134.56	130.87	128.07	123.26
11	5NE	CUMBRIA TEACHING PCT	128.19	124.64	121.12	117.07	116.22	109.81	119.51
12	5NF	NORTH LANCASHIRE TEACHING PCT	99.58	106.44	125.54	124.95	116.44	123.38	116.05
13	5NG	CENTRAL LANCS PCT	112.62	116.74	119.10	129.88	115.52	124.70	119.76
14	5NH	EAST LANCASHIRE TEACHING PCT	140.95	117.57	157.57	162.52	159.26	154.85	148.78
15	5NJ	SEFTON PCT	197.04	132.99	149.26	145.29	117.47	147.48	148.25
16	5NK	WIRRAL PCT	182.27	179.53	172.71	201.85	198.35	208.95	190.61
17	5NL	LIVERPOOL PCT	221.47	221.68	199.18	214.04	208.77	184.19	208.22
18	5NM	HALTON & ST HELENS PCT	139.79	172.26	156.64	170.58	176.31	178.44	165.67
19	5NN	WESTERN CHESHIRE PCT	122.36	138.36	160.12	142.43	116.65	112.87	132.13
20	5NP	CENTRAL AND EASTERN CHESHIRE PCT	118.29	151.78	169.47	169.06	127.91	113.54	141.67
21	5NQ	HEYWOOD MIDDLETON & ROCHDALE PCT	149.85	166.30	156.41	180.94	166.74	166.23	164.41
22	5NR	TRAFFORD PCT	110.74	118.93	131.68	122.72	138.56	122.80	124.24
23	5NT	MANCHESTER PCT	201.31	207.09	187.70	211.74	214.17	220.78	207.13
24	5NV	NORTH YORKSHIRE AND YORK PCT	90.96	94.12	101.95	100.01	102.39	94.43	97.31
25	5NW	EAST RIDING OF YORKSHIRE PCT	114.17	124.81	110.80	138.35	118.07	98.04	117.37
26	5NX	HULL TEACHING PCT	241.01	253.06	267.93	265.61	266.75	259.76	259.02
27	5NY	BRADFORD & AIREDALE PCT	148.08	165.34	157.89	169.81	169.87	144.75	159.29
28	5P1	SOUTH EAST ESSEX PCT	98.24	102.06	97.80	108.26	106.68	107.86	103.48
29	5P2	BEDFORDSHIRE PCT	86.22	93.55	94.34	96.33	96.98	97.17	94.10
30	5P5	SURREY PCT	80.67	90.60	92.57	91.49	89.52	89.18	89.00
31	5P6	WEST SUSSEX PCT	93.45	107.32	113.23	114.08	114.81	104.84	107.96
32	5P7	EAST SUSSEX DOWNS & WEALD PCT	97.36	100.97	91.31	96.44	89.36	114.55	98.33
33	5P8	HASTINGS & ROTHER PCT	148.50	139.08	149.15	142.16	108.40	99.70	131.17
34	5P9	NHS WEST KENT	98.65	102.34	103.88	102.28	106.01	106.40	103.26
35	5PA	LEICESTERSHIRE COUNTY & RUTLAND PCT	94.01	88.73	85.02	93.97	94.92	101.39	93.01
36	5PC	LEICESTER CITY PCT	178.49	167.97	174.86	173.85	181.37	158.26	172.47
37	5PD	NORTHAMPTONSHIRE PCT	80.55	100.10	95.82	100.04	98.69	103.81	96.50
38	5PE	NHS DUDLEY	99.62	96.40	110.46	133.36	134.91	117.24	115.33
39	5PF	SANDWELL PRIMARY CARE TRUST	157.01	149.68	138.64	160.49	159.34	148.93	152.35
40	5PG	BIRMINGHAM EAST AND NORTH PCT	152.18	163.95	174.54	186.94	154.28	155.80	164.61
41	5PH	NORTH STAFFORDSHIRE PCT	107.27	121.01	124.77	117.93	100.54	122.75	115.71
42	5PJ	STOKE ON TRENT PCT	163.92	150.48	182.22	164.52	181.56	191.35	172.34
43	5PK	SOUTH STAFFORDSHIRE PRIMARY CARE TRUST	93.83	96.90	103.67	105.69	109.12	114.55	103.96
44	5PL	NHS WORCESTERSHIRE	95.82	112.25	117.63	105.51	101.57	126.58	109.89
45	5PM	WARWICKSHIRE PCT	94.87	94.66	111.07	129.61	104.05	113.08	107.89
46	5PN	PETERBOROUGH PCT	113.44	122.83	116.71	104.66	118.20	95.01	111.81
47	5PP	CAMBRIDGESHIRE PCT	79.20	84.00	93.51	96.47	100.95	91.66	90.97
48	5PQ	NORFOLK PRIMARY CARE TRUST	87.48	84.70	83.37	87.38	95.10	95.77	88.97
49	5PR	GREAT YARMOUTH AND WAVENEY PCT	111.14	122.89	113.88	121.77	147.19	150.07	127.82
50	5PT	SUFFOLK PCT	79.08	88.16	93.11	98.85	97.23	96.04	92.08
51	5PV	WEST ESSEX PCT	93.05	77.56	93.83	107.21	113.62	94.60	96.65
52	5PW	NORTH EAST ESSEX PCT	87.79	84.96	116.04	101.69	120.40	120.24	105.19
53	5PX	MID ESSEX PCT	82.08	122.96	119.77	103.47	88.04	89.39	100.95
54	5PY	SOUTH WEST ESSEX PCT	86.82	83.28	82.95	85.21	86.72	90.51	85.92
55	5QA	NHS EASTERN & COASTAL KENT	132.38	132.82	134.03	144.30	152.08	150.08	140.95
56	5QC	HAMPSHIRE PRIMARY CARE TRUST	81.16	93.22	101.96	99.37	101.02	101.52	96.38
57	5QD	BUCKINGHAMSHIRE PCT	76.04	78.68	69.36	64.33	78.94	74.15	73.58
58	5QE	OXFORDSHIRE PRIMARY CARE TRUST	97.18	102.20	109.93	91.21	95.80	99.97	99.38
59	5QF	BERKSHIRE WEST PRIMARY CARE TRUST	61.84	63.97	67.50	68.61	66.68	72.46	66.84
60	5QG	BERKSHIRE EAST PRIMARY CARE TRUST	67.94	82.42	79.73	87.09	106.79	102.57	87.76
	5QH	GLOUCESTERSHIRE PCT	67.93	77.30	77.54	99.18	107.96	99.24	88.19
	5QJ	BRISTOL PCT	145.77	158.63	153.99	146.35	154.73	140.78	150.04
	5QK	WILTSHIRE PCT	90.35	96.90	95.36	95.34	103.96	111.77	98.95
	5QL	SOMERSET PRIMARY CARE TRUST	86.78	108.93	116.83	115.51	125.30	126.91	113.38
	5QM	DORSET PRIMARY CARE TRUST	80.80	75.37	88.75	87.30	110.26	110.32	92.13
	5QN	BOURNEMOUTH AND POOLE TEACHING PCT	136.15	140.44	159.23	185.88	172.48	164.26	159.74
	5QP	CORNWALL AND ISLES OF SCILLY PCT	115.23	105.72	103.19	109.52	111.54	112.98	109.69
	5QQ	DEVON PRIMARY CARE TRUST	107.39	97.62	95.04	103.93	106.75	110.78	103.58
	5QR	REDCAR AND CLEVELAND PCT	167.53	148.40	137.60	131.31	157.97	141.06	147.31
	5QT	ISLE OF WIGHT NHS PCT	61.77	105.91	100.11	130.41	107.42	105.05	101.78
	5QV	HERTFORDSHIRE PCT	80.23	82.68	91.78	96.45	105.92	106.49	93.92
	5QW	SOLIHULL PCT	213.26	198.25	169.40	199.13	159.04	170.58	184.94
	TAC	NORTHUMBERLAND CARE TRUST	129.24	134.05	104.36	113.49	142.63	130.17	125.66
	TAK	NHS BEXLEY	65.29	70.62	65.29	68.93	64.34	95.93	71.74
	TAL	TORBAY CARE TRUST	143.72	167.82	134.41	155.18	176.78	179.19	159.52



1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

TAN	NORTH EAST LINCOLNSHIRE CARE TRUST PLUS	108.75	98.22	120.78	116.65	148.62	113.04	117.68
TAP	BLACKBURN WITH DARWEN PCT	145.44	145.57	183.70	202.98	193.03	202.34	178.85

For peer review only

The RECORD statement – checklist of items, extended from the STROBE statement, that should be reported in observational studies using routinely collected health data.

Item No.	STROBE items	Location in manuscript where items are reported	RECORD items	Location in manuscript where items are reported
<b>Title and abstract</b>				
1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found	pgs 1-2	RECORD 1.1: The type of data used should be specified in the title or abstract. When possible, the name of the databases used should be included.  RECORD 1.2: If applicable, the geographic region and timeframe within which the study took place should be reported in the title or abstract.  RECORD 1.3: If linkage between databases was conducted for the study, this should be clearly stated in the title or abstract.	pg 2  pg 2  n/a
<b>Introduction</b>				
2	Explain the scientific background and rationale for the investigation being reported	pg 4		pg 4
3	State specific objectives, including any prespecified hypotheses	pg 4		pg 4
<b>Methods</b>				
4	Present key elements of study design early in the paper			pgs 4-6
5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection			pgs 4-6
6	(a) <i>Cohort study</i> - Give the		RECORD 6.1: The methods of study	

		<p>eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up</p> <p><i>Case-control study</i> - Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls</p> <p><i>Cross-sectional study</i> - Give the eligibility criteria, and the sources and methods of selection of participants</p> <p>(b) <i>Cohort study</i> - For matched studies, give matching criteria and number of exposed and unexposed</p> <p><i>Case-control study</i> - For matched studies, give matching criteria and the number of controls per case</p>	<p>4-6</p>	<p>population selection (such as codes or algorithms used to identify subjects) should be listed in detail. If this is not possible, an explanation should be provided.</p> <p>RECORD 6.2: Any validation studies of the codes or algorithms used to select the population should be referenced. If validation was conducted for this study and not published elsewhere, detailed methods and results should be provided.</p> <p>RECORD 6.3: If the study involved linkage of databases, consider use of a flow diagram or other graphical display to demonstrate the data linkage process, including the number of individuals with linked data at each stage.</p>	<p>4-6</p>
Variables	7	<p>Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable.</p>		<p>RECORD 7.1: A complete list of codes and algorithms used to classify exposures, outcomes, confounders, and effect modifiers should be provided. If these cannot be reported, an explanation should be provided.</p>	<p>4-6</p>
Data sources/ measurement	8	<p>For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group</p>			<p>4-6</p>
Bias	9	<p>Describe any efforts to address potential sources of bias</p>			<p>4-6</p>

Study size	10	Explain how the study size was arrived at			NA
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why			pg 4-6
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) <i>Cohort study</i> - If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> - If applicable, explain how matching of cases and controls was addressed <i>Cross-sectional study</i> - If applicable, describe analytical methods taking account of sampling strategy (e) Describe any sensitivity analyses			pg 4-6
Data access and cleaning methods		..		RECORD 12.1: Authors should describe the extent to which the investigators had access to the database population used to create the study population.  RECORD 12.2: Authors should provide information on the data cleaning methods used in the study.  RECORD 12.3: State whether the	pg 4-6
Linkage		..			

					study included person-level, institutional-level, or other data linkage across two or more databases. The methods of linkage and methods of linkage quality evaluation should be provided.	11A
Results						
Participants	13	(a) Report the numbers of individuals at each stage of the study (e.g., numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed) (b) Give reasons for non-participation at each stage. (c) Consider use of a flow diagram	Fig 6-7	RECORD 13.1: Describe in detail the selection of the persons included in the study (i.e., study population selection) including filtering based on data quality, data availability and linkage. The selection of included persons can be described in the text and/or by means of the study flow diagram.		Fig 6-7
Descriptive data	14	(a) Give characteristics of study participants (e.g., demographic, clinical, social) and information on exposures and potential confounders (b) Indicate the number of participants with missing data for each variable of interest (c) Cohort study - summarise follow-up time (e.g., average and total amount)	Fig 6-7			
Outcome data	15	Cohort study - Report numbers of outcome events or summary measures over time Case-control study - Report numbers in each exposure category, or summary measures of exposure Cross-sectional study - Report numbers of outcome events or	Fig 6-7			

Main results	16	summary measures (a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	Pg 6-7			
Other analyses	17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses	Pg 6-7			
<b>Discussion</b>						
Key results	18	Summarise key results with reference to study objectives	Pg 7-9			
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	Pg 7-9 Pg 3		RECORD 19.1: Discuss the implications of using data that were not created or collected to answer the specific research question(s). Include discussion of misclassification bias, unmeasured confounding, missing data, and changing eligibility over time, as they pertain to the study being reported.	
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Pg 7-9			

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

Generalisability	21	Discuss the generalisability (external validity) of the study results	Fig 7-a		
Other Information					
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	Fig 9		
Accessibility of protocol, raw data, and programming code		..		RECORD 22.1: Authors should provide information on how to access any supplemental information such as the study protocol, raw data, or programming code.	Fig 9

\*Reference: Benchimol EI, Smeeth L, Guttman A, Harron K, Moher D, Petersen I, Sørensen HT, von Elm E, Langan SM, the RECORD Working Committee. The REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) Statement. *PLoS Medicine* 2015; in press.

\*Checklist is protected under Creative Commons Attribution (CC BY) license.